

California Department of Social Services and Child Welfare Council Data Linkages Project



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California Department of Social Services and Child Welfare Council Data Linkages Project

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Disclaimer: The opinions expressed in this document are those of the authors and not necessarily of the California Department of Social Services or the Child Welfare Council.



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INTRODUCTION

Improved coordination and collaboration among the government agencies that promote the well-being of vulnerable children have long been among California's top priorities. These goals are based on acknowledging that the needs of children are not compartmentalized, but span the breadth of services and supports provided by the State. Indeed, the well-being indicators developed by the California Health and Human Services Agency (HHS) Child Welfare Outcomes and Accountability Workgroup were designed to cover multiple life domains and to be consistent with the requirements of Assembly Bill 636 (AB 636-Steinberg). AB 636 provides a framework for action toward accountability, requiring HHS to establish a plan by which outcome-based reviews would be conducted in all counties.

The difficulty inherent in such an effort arises from the fact that individual agencies' data systems were not, for the most part, designed to produce outcome data, or with data sharing explicitly in mind. Achieving the State's ultimate goal of addressing these well-being indicators accurately and efficiently will therefore require a long-term effort. Among the State's earliest steps in initiating this long-term effort was the HHS Workgroup's formation of the State Interagency Team (SIT), whose aim was to continue developing the child well-being indicators developed by the Workgroup, as well as to begin investigating access to data relevant to those indicators. In 2006, SIT charged the California Department of Social Services (CDSS) with coordinating these efforts and undertaking an analysis of the key data systems maintained by a variety of state agencies. With the assistance of appropriate staff from those agencies, CDSS's primary objective was to identify the potential for using these data systems to augment and/or validate AB 636 reporting.

In April of 2006, CDSS made a formal request to the University of California, Davis Center for Public Policy Research (CPPR) for technical assistance on this project. CPPR was officially contracted to perform the following functions:

- Assess possibilities and make recommendations for integration and shared data management among state agencies to better realize AB 636 outcome measures,

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- Investigate and propose opportunities for data integration and utilization, and
- Identify other information available on AB 636 issues.

CPPR's December 2006 report, *Interagency Measurement of Child Well-Being*, served as a summary of findings and recommendations stemming from these investigations and can be accessed online at www.chhs.ca.gov/initiatives/CACChildWelfareCouncil/Documents/CPPRSITFinalReport.pdf. To briefly review key findings, CPPR concluded that:

- Data were available within CDSS or other SIT member agencies to adequately address 18 of the 33 AB 636 well-being indicators.
- Of the agencies investigated by CPPR, the four that maintain data most relevant to AB 636 reporting were the California Departments of Social Services (CDSS), Health Services (DHS), Mental Health (DMH), and Education (CDE).
- All of the agencies with which CPPR met expressed support for SIT's effort, as well as a desire to contribute to CDSS's investigations, a desire to share data, and a thorough understanding of the challenges inherent in such efforts.
- Issues related to privacy and confidentiality—which are often cited as “road blocks” to the sharing of administrative data between government agencies—are not insurmountable. Internal data merging and de-identification can be performed prior to data

As any of these approaches will require a fair degree of time and human resources, the next step for CDSS and other SIT member agencies is to reach an agreement on where those human resources will come from, what current or future personnel would be needed, and whether further funding will be necessary. Addressing the AB 636 indicators once will require a certain degree of commitment; setting up a process by which the tracking and sharing of data related to CWS children can take place regularly, efficiently, and more thoroughly than possible at the present time will take a long-term commitment from HHSA and several of its constituent agencies. (CPPR, 2006)

release, contracts or Memorandums of Understanding (MOUs) can be set up between CDSS and other departments, and analyses can take place within other departments with CDSS then receiving *analysis results* rather than *raw data*.

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Also crucial to the current report is an acknowledgment of the recommendations made by CPPR based on these findings, the majority of which are *as or more* relevant today as they were over two years ago. These recommendations, as given to CDSS, were as follows:

1. Establish MOUs with DHS, DMH, and CDE. Along with data possessed by CDSS in the Child Welfare Services/Case Management System (CWS/CMS), data within DHS, DMH, and CDE are the most relevant to AB 636 well-being indicators. In the course of CPPR's investigations, DHS, DMH, and CDE all expressed a keen interest in collaborating with CDSS to locate and track children involved with child welfare services within their own systems. Representatives from DHS also expressed a strong desire to work with CDSS on issues above and beyond AB 636, noting the high degree of overlap in the adult and child populations served by both departments. In establishing MOUs, decisions will need to be made regarding, for example, where relevant work will be located.
2. Resolve Issues Related to Data Integration and Confidentiality. Most, if not all, of the agency representatives involved with this report cited confidentiality as a fundamental concern in terms of data sharing among departments. Analysis must therefore be completed to determine what can and cannot be shared across agencies, and the most feasible and responsible strategies for working within current data confidentiality guidelines. These strategies might include the conducting of surveys, de-identification of individual clients' data, or the sharing of aggregate information between departments.
3. Clarify AB 636 Well-Being Indicators. The 15 indicators written by the Accountability Workgroup were designed with best practices in mind, rather than the existence of data needed to operationalize them. Although CPPR supports the Workgroup members' efforts to be broad and inclusive in their discussions of well-being, advancement from this point would be aided by a thorough review of these indicators. Such a review should be undertaken with an eye toward improving their clarity and specificity, and determining which indicators are the most crucial to pursue at this time.
4. Improve the Process By Which Data Are Gathered, Entered, and Analyzed in CDSS's CWS/CMS. Currently, any new well-being measures developed by CDSS's AB 636 data subcommittee are accompanied by an All County Information Notice to provide county child welfare agencies specific instructions for entering information into CWS/CMS. It is anticipated that this practice will result in more consistent information being entered into

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the system, therefore making the data more reliable. If improvements continue to be made in the thoroughness and reliability of CWS/CMS data, it is theoretically possible for CDSS to address at least 14 of the 33 outcomes investigated by CPPR—with data from other state agencies, perhaps, serving to augment or validate this CWS/CMS information.

5. Decide Upon the Degree to Which Sampling Is or Is Not Acceptable As a Strategy For Addressing Child Well-Being Indicators. CDSS currently conducts a statistically valid annual survey of birth and foster parents to obtain well-being information specific to assessment for and receipt of educational, health, and mental health services. Therefore, consideration should be given to the feasibility of adding items regarding perceived access to these support services (e.g., as reflected in certain indicators), as such information is unlikely to be accessible in any administrative database. Similarly, there are several education-related indicators that cannot be matched at the individual level and do not exist at the state level, but may be accessible in some form at the district level. A crucial next step for CDSS would be to reach a definitive agreement (either internally or with state or federal officials) on whether or not it would be acceptable under the new outcomes and accountability system to address some of the indicators via a representative sample of specific groups.
6. Determine the Feasibility of Creating a Centralized Data Warehouse. States have long investigated the feasibility of integrating existing databases in a central location, either once (for the purposes of one-time research or evaluation) or in an on-going fashion. The latter approach would enable independent evaluators and/or the agencies themselves to ask and answer a range of questions about the individuals served. Data warehousing could either be limited to the specific variables determined to be directly relevant to the tasks of matching and outcome analysis; or the approach could be more ambitious, feeding entire de-identified datasets into a centralized location on an on-going basis. Confidentiality would be of paramount importance in any warehousing arrangement, with the data needing to be de-identified and/or the security of the server assured. Issues of reliability, linkage, and coding schemes would present further challenges and would require the ongoing commitment of all involved agencies. Several states have included the investigation of data integration in their Program Improvement

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Plans (PIPs), and some California counties have already attempted the warehousing of cross-agency data. Analyses of their experiences could prove extremely valuable.

The California Child Welfare Council's Statement on Data Sharing

In addition to the findings of the first CPPR report, CDSS's current research request has been influenced by the draft "Statement on Data Sharing" of the Data Linkage and Information Sharing Committee of the California Child Welfare Council (CWC). In this statement, the committee strongly affirmed its "commitment to the exchange of child welfare information between federal and state government, tribes and tribal organizations, local public entities, the courts, and authorized child-serving private entities." Through this statement, the committee also:

1. Acknowledged the importance of legal protections concerning the confidentiality of data and right to privacy of children and families served by state agencies and private providers;
2. Noted the ongoing development of new case management systems for the California courts and child welfare services;
3. Joined the Blue Ribbon Commission in endorsing joint planning of these new case management systems, so as to allow for appropriate data exchange that maximizes the information available and meets the federal outcome measures specified in the Child and Family Services Reviews (CFSRs) and the State's Child Welfare Outcomes and Accountability System;
4. Delineated its vision for comprehensive information sharing through integrated systems and within workplaces dedicated to routine and systemic sharing across jurisdictional boundaries while ensuring confidentiality and legal protections for children, families, and caregivers with respect to personal and sensitive information; and, perhaps of most importance,
5. Recommended moving forward aggressively to expand existing information sharing capacities and capabilities to permit each entity to participate more fully and uniformly in information sharing efforts and to draw upon existing relationships and agreements whenever possible to lend leadership and assistance to implementation.

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The Current Report

Since the release of CPPR's 2006 report, the issue of data sharing (particularly as it relates to the tracking of children and the measurement of child well-being) has evolved. The term "data sharing" can be defined as the sharing of the same data or data resources, either at the individual or aggregate level, with multiple users or applications. Where federal, state, and local governments once questioned whether or not they *should* share data, the debate is now focused on the soundest *strategies* for doing so—quickly, efficiently, legally, and in ways that benefit all interested parties.

Data that exist in a single agency, or in a single program of an agency, are no longer seen as sufficient to document the impact of increasingly complex programs or to answer the complex questions being asked about the impact of these programs. (Flango, 2008, p. iv)

Similarly, the driving question for CDSS and the State of California has gone from one of "Can we...?" to the current question of "How can we...?" To that end, CDSS once again contracted with CPPR to return to each of the departments visited during their initial investigations, to expand investigations to additional entities, to gather information on county and state "best practices" regarding data sharing, and to move California closer to a data sharing strategy that is achievable in light of extant data practices, current legislation, federal and self-imposed mandates, and a genuine concern for the well-being of the millions of children and families who come in contact with state-associated services every day.

In summary form, CDSS requested that CPPR:

1. Conduct an "environmental scan" to identify federal and state data reporting requirements and performance measurements from each of the departments represented on the CWC that would mutually benefit from, as well as assist each other in, meeting those requirements and measurements;
2. Research case management and data collection technology and capabilities in each agency or jurisdiction;
3. Research promising practices on both the aggregate and case levels where data sharing has been successful;

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4. Conduct research to identify and inventory the data integration and information sharing barriers existing or perceived to exist between each of the departments represented on the CWC;
5. Identify approaches and strategies that have been successfully implemented by other departments to overcome barriers to data integration and information sharing;
6. Produce a report outlining the findings and recommendations of the conducted research;
7. Present findings to the CWC.

To this end, CPPR undertook research and investigations (via single and multiple rounds of face-to-face and telephone interviews throughout the summer and fall of 2008) with the following state entities:

- The Department of Mental Health (DMH),
- The Administrative Office of the Courts (AOC),
- The Department of Education (CDE),
- The Department of Health Care Services (DHCS),
- The Department of Public Health (CDPH),
- The Department of Alcohol and Drug Programs (ADP),
- The Department of Corrections and Rehabilitation (CDCR), and
- The Department of Developmental Services (DDS).

The following report offers a department-by-department overview of findings, an in-depth discussion of state and county best practices from around the country, and concluding comments relative to policy implications and possible next steps for CDSS, SIT, the HHS's workgroup, and the state as a whole. Each departmental chapter was written with the goals of 1) providing additional or updated descriptive information on the department's data systems, 2) making arguments for and against the logic of data sharing between the department and CDSS (i.e., the relevance of the department's data to children and families involved with the child welfare system), and 3) to the extent possible, providing enough insights into the given department's current data systems and current state of mind to allow for an understanding of what the first reasonable or expected steps toward data sharing might be. For example, if a department used the exact data formats and unique identifiers as does the CWS/CMS system,

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the primary obstacle to data sharing might relate to confidentiality or other legal concerns. If the data are under no legal constraints, the issues brought to the fore may be more technological in nature (e.g., incompatible data formats). Alternatively, the issues highlighted might have to do with the budgetary and human resources needed to update one system or perform probabilistic matching. In other words, although it was not CPPR's mandate to provide department-by-department blueprints for data exchange, each chapter aims to capture the orientation of the representatives from each department—meaning, *With which primary points of enthusiasm or primary points of concern did they lead?*

The primary points of enthusiasm (motivating drives toward data sharing) repeatedly encountered by CPPR had to do with the desire to have systems of service and systems of data collection that, quite simply, made sense. Sometimes these “logic models” were founded on the department’s mission statement (i.e., What do we have a responsibility to do?); other times they stemmed from an understanding of modern business operating practices (i.e., How can advanced technology help large organizations streamline operations and achieve greater gains?) Looking at the former, many departmental representatives expressed frustration at their inability to meet the needs of their vulnerable client populations at the highest possible level of service (a “client-oriented” perspective). When both research and anecdotal evidence demonstrates that the types of clients coming into contact with one department (e.g., AOC) are highly likely to have contact with another department (e.g., CDSS), the very fact that those departments do not systematically “speak” to one another raises concerns about coverage of care. The well-known phrase “falling through the cracks” relates to these gaps in service systems. Duplication across departments of service can also lead to frustration for parents and children, as well as unnecessary expenses for agencies.

Looking at the issue of data sharing from a more operations-oriented (as opposed to client-oriented) perspective, much of the frustration expressed by departmental representatives stemmed from their deep and long-standing awareness of the inefficiencies built into the current systems, including inefficiencies in internal data practices (i.e., data collection, data definitions, data storage and maintenance). Such inefficiencies not only impede systematic data exchange, they tax human resources, waste time, create unnecessary complications, and—in the worst

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cases—can lead to poor performance. Although California has spent much of the past 20 years successfully transforming its data into digital formats, rapid change and competing agendas led to the neglect of issues related to data exchange across applications—even *within* a given department. As a result, not enough standardization of key elements exists: data dictionaries vary, formats differ, and programming languages prove incompatible. Although the California Records and Information Management (CalRIM) unit within General Services has statutory authority to develop standards, the law does not *require* departments to follow those standards (Gov. C. Section 14740), and thus each department has followed its nose, adopting and sticking with systems that worked and were available at the time.

Sticking with what worked at one point in time will invariably prove problematic if not fatal once the operational environment changes. To stay viable and effective, systems must continue to develop and evolve as environmental factors change. Yet—where the business world has leapt on technological advancements—large government bureaucracies have often had a more troubled relationship with change due to the absence of profit as a motivator. This cannot and should not be the case when the issues at stake are so crucial.

Given these arguments in favor of data sharing, both moral and practical, the question becomes one of impediments, both real and perceived. These impediments, barriers, and roadblocks tend to fall into the categories of organizational/structural, legislative, and resource-related. These categories are highly interrelated: If a system is set up to funnel all data into the warehouse of a single umbrella organization, rules related to data sharing might not apply. If funding was available to resolve the technological differences between departmental data systems, it would be far easier to work with and around various legislative barriers. If experts in each department's data systems were permitted (or required) to sit down together and design 10 year plans for data integration, the technological roadmaps needed to support legislative change would be in place. This interrelatedness of impediments is good news, however, in that any comprehensive plan for data sharing between CDSS and another department will likely be forced to address barriers from structural, legal, and technological points of view—and will thus be applicable to the data sharing barriers encountered by other entities, departments, or agencies.

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Best Practices

In the hopes of encouraging the development of such plans, a lengthy section on data sharing best practices has been included in the current report. The particular state and county examples that have been included were chosen to demonstrate a variety of *pathways into* data sharing (i.e., What tipped the scales in favor of systemic change?), as well as a variety of *roads toward* successful data sharing (i.e., What specific steps are being taken to realize that goal?) It is CPPR's belief that the sheer size of California, the disparate nature of its agencies' and counties' long-standing data systems, and the current environment of budgetary cutbacks will require a creative combination of several of these best practices. The key point, however, is that the departments, counties, and states covered in this section all have one fundamental best practice in common: Somewhere along the line, a firm decision to share data was made. From there the lessons learned are informative but not required, and will be more or less relevant to counties versus the State, to one department versus another, and so forth. It is also important to note that the best practices covered in this report deal largely with data sharing arrangements that were meant to be fairly narrow in scope—for example, unilateral data sharing between only two departments. This means that California is in the unique position to utilize these small scale lessons in the establishment of a larger roadmap for state-level data sharing.

Conclusion

In crafting the current report, CPPR's overarching goal was to support CDSS and the CWC in their decision to move the debate about data sharing from one of *Can we?* to one of *How can we?* To the extent possible, this means making department-specific arguments for the benefits of data sharing, detailing current systems, discussing existing roadblocks, and relating the case of Department A to the successful practices already undertaken by Entity B (whether agency, county, or state). Some of this will be done on a chapter-by-chapter basis, some will come together in the form of broader policy and practice recommendations provided at the end of the report.

In our current research, state agencies revealed some movement toward improved data sharing relative to the findings of the 2006 CPPR report, including new inter-departmental MOUs and increased expertise about confidentiality laws and regulations. However, significant roadblocks,

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such as isolated systems, budgetary resources, and data reliability from local jurisdictions (i.e., county and regional agencies) persist and create structural challenges that will require long-term strategies. Examples from other states (e.g., Colorado, Utah) and select California counties (i.e., Los Angeles, San Diego, Santa Clara, San Mateo) included in this report indicate that multi-agency data sharing agreements, usually involving both MOUs and court orders, can be applied to deliver multi-disciplinary information for legal, social welfare, education, and health practitioners. These examples may provide interim solutions for proximate data sharing objectives while long-term structural data linkage goals are pursued.

It should be noted that although the present document was commissioned by CDSS, the issues go well beyond that agency's reach. The data sharing possibilities and mechanisms discussed can, in principle, greatly benefit other California agencies and departments, for example, in their need to establish or comply with performance measures, ensure informed program planning, and provide optimal services for children and families throughout the State.

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CALIFORNIA DEPARTMENT OF MENTAL HEALTH

Children who require child welfare services are at high risk of exhibiting mental health problems and thus are often in need of mental health services. For example, a national study revealed that rates of emotional and behavioral problems documented in children in foster care are higher than the 11% to 39% prevalence rates obtained from community samples that include children living in poverty (Leslie et al., 2003). A recent study in California of women who, in childhood, had experienced out-of-home placement (compared to those who had not) found that the former were significantly more likely to report frequent mental distress and were approximately three times more likely to have symptoms of Post-Traumatic Stress Disorder (PTSD), even with factors such as age and race/ethnicity statistically controlled (Schneider et al., in press). In California, almost 50% of all Medi-Cal eligible foster children receive one or more mental health service (California Mental Health Planning Council, 2007).

DMH creates and manages partnerships to ensure the availability and accessibility of effective, efficient, culturally competent mental health services, including services to children in California's child welfare system. This is accomplished with advocacy, education, innovation, outreach, understanding, oversight, monitoring, quality improvement, and the provision of direct services. California's public mental health system offers an array of community and hospital-based services, including rehabilitation and support, evaluation and assessment, individual service planning, medication, education, case management, and wrap-around services, that are available to adults who have serious mental illnesses and children with severe emotional disorders. DMH is responsible for:

1. Providing leadership for local county mental health departments;
2. Evaluating and monitoring public mental health programs;
3. Administering federal funds for mental health programs and services;
4. The care and treatment of people with mental illness at the five state mental hospitals (Atascadero, Metropolitan, Napa, Coalinga, and Patton State Hospitals) and at the Acute Psychiatric Programs located at the California Medical Facilities in Vacaville and Salinas Valley; and

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5. Implementing the Mental Health Services Act of 2004 (Proposition 63), which provides State tax dollars for specific county mental health programs and services.

Purpose and Goals

On October 23 and 28, 2008, meetings took place between CPPR personnel and representatives from DMH. Attendees from each agency were as follows:

Department of Mental Health

October 23, 2008

Denise Arend, Deputy Director of Community Services

Denise Blair, Deputy Director of Information Technology

Elaine Bush, Chief Deputy Director

Sean Tracy, Special Projects Manager, Office of Strategic Planning and Policy

October 28, 2008

Marc E. Grimm, Chief of Research and Evaluations

Marti Johnson, Acting Chief of Performance Outcome and Quality Improvement Unit

Center for Public Policy Research

Gail S. Goodman, Director/Principal Investigator

Michael J. Lawler, Co-Director/Co-Principal Investigator

Shay K. O'Brien, Senior Writer

Jillian Ducker, Research Analyst

The primary purpose of these meetings was for CPPR to follow up on the previous CDSS SIT investigations into data systems relevant to the AB 636 child well-being indicators, as well as data used by CDSS in the course of the annual, federally mandated CFSR.

Attendees of this meeting explored further data sharing possibilities and discussed the potential benefits of linking statewide data systems. CPPR's goals for this meeting were as follows:

- To update information on DMH data systems as originally summarized in a CPPR report entitled *Interagency Measurement of Child Well-Being*, dated December 2006.

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- To obtain information about current data sharing practices and standards.
- To identify barriers (e.g., confidentiality, privacy) to information sharing across agencies.
- To assess data integration and shared data management possibilities between DMH and CDSS.
- To delineate the potential benefits of sharing data for DMH, their stakeholders, and other departments and agencies across the state.

Overview of Findings

DMH has an MOU with CDSS regarding the sharing of DMH and foster care data (Appendix A). This MOU serves as a potential model for MOUs with other state departments and agencies. As described in greater detail later in this chapter, the MOU facilitates access to confidential data for program monitoring and health oversight of children receiving child welfare services, in accordance with the Health Insurance Portability and Accountability Act (HIPAA) Code 45 CFR 164.512(d) and to comply with the Mental Health Services Act of 2004, Proposition 63.

Representatives from DMH indicated having a broad interest in data sharing with other state agencies as well. In particular, the sharing of data with the Department of Justice (DOJ) and CDCR would allow for a useful examination of the intersection between various manifestations of mental illness, criminal behavior, and contact with the justice system. Also discussed were the potential benefits of data sharing with ADP, as a high percentage of individuals with mental illness evince co-occurring substance abuse and addiction problems. DMH representatives felt that the sharing of data between these departments could improve the consistency and efficacy of state services for individuals with these co-occurring disorders.

Subsequent to CPPR's initial report in 2006, the DMH received additional mandates through the Mental Health Services Act of 2004 (Proposition 63), which led to the creation of a unique database. DMH representatives stated that the resulting Data Collection and Reporting System (DCR) is now collecting consistent, high-quality data on client outcomes in eight life domains. Full participation in the new system had not occurred at the time of the interview, but DMH anticipates that all counties with Full Service Partnerships will be reporting to the DCR by the release of the current report.

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Current Data Collection Practices and Projects

DMH is required to collect and report data on services delivered through the public mental health system, as established by AB 1288 (Bronzan, Chapter 89, Statutes of 1991), commonly known as “Realignment.” Additionally, as a condition of receiving federal Substance Abuse and Mental Health Services Administration (SAMHSA) funds, DMH must also be responsive to federal performance reporting initiatives and incorporate into practice the nationally derived accountability indicators set forth by SAMHSA and Title XIX of the Social Security Act.

In the broadest terms, DMH serves as both data collector and secondary data repository, receiving a subset of Medi-Cal billing and related data, as well as data from various county mental health administrations. Data elements and links to online data dictionaries for these databases can be found in Appendix B.

Client and Service Information System (CSI)

The CSI is a statistical information system that includes data on all persons served in public county mental health programs in California. On average, CSI has 600,000 unduplicated client records and 19 million services per fiscal year. There are three types of records reported to CSI:

1. *Client records*, which include client characteristics, such as date of birth, race/ethnicity, and language;
2. *Service records*, which include information about the service encounter, such as date of service, type of service, and diagnosis; and
3. *Periodic records*, which include types of client data that are collected less frequently, such as living situation and employment status.

County programs report CSI data monthly via DMH’s Information Technology Webserver (ITWS). Summary statewide and county reports are also provided to counties via the ITWS.

DMH representatives indicated that the CSI is limited by a lack of incentive for counties to report data to this file, resulting in a low reporting rate and inconsistent data collection. These data have the additional limitation of emerging from a collection system primarily designed to gather and track billing information, making it difficult to utilize the dataset for the purposes of outcome evaluation or the assessment of client status changes. As new federal requirements are

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developed, data used for outcome indication are often dropped, resulting in a decrease of information through CSI relative to the potential effectiveness of DMH services.

Short-Doyle Medi-Cal Approved Claims

Counties submit claims through the ITWS to DMH for services provided by county mental health and contract providers. DMH, in turn, submits the claims to DHCS for processing in a separate system known as Short-Doyle/Medi-Cal (SD/MC). DHCS adjudicates the claims and provides a file back to DMH on the approval or denial status of the claims. These files are then returned to the counties. Claims data include information identifying the client, the services provided, diagnosis, amount claimed, and amount approved. HIPAA requires that health insurance payers in the US comply with electronic data interchange (EDI) standards. In July of 2007, all counties and their vendors began submitting electronic health care data to DMH in a mandated HIPAA format. The SD/MC is comprised of data that are required to meet HIPAA validation standards.

Data Collection and Reporting System (DCR)

The DCR contains individual-level data regarding participants in Full Service Partnerships funded through the Mental Health Services Act of 2004, Proposition 63 (available at http://www.dmh.ca.gov/prop_63/MHSA/default.asp). This system is designed to measure changes in eight life domains: living situation, education, employment, financial support, legal issues, emergency intervention, health, and substance abuse. These data are collected over time, with collection occurring both at the event and at three month intervals. Currently, DCR contains about 47,000 records for over 8,000 individuals—although DMH representatives expect these numbers to double in the next few years.

DMH representatives also indicated that this database contains the highest-quality mental health-related data currently collected. However, due to technical difficulties and variations in procedures, only about 50% of California counties are reporting data to this system. At the time of this report, counties were able to submit data via direct on-line key entry or in batch form. DMH representatives stated that all 50 counties operating Full Service Partnerships were on target to submit data on a regular basis by the end of 2008. Once all the counties are submitting

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data, additional high-quality analyses will need to be performed to ensure that the data in the system are reliable and effective.

Web-Based Data and Reporting System (WBDRS)

The WBDRS contains individual-level data on quality of life and satisfaction with mental health services, as reported by clients and their families through various consumer perception surveys. More specifically, these data are collected via the Youth Services Survey for Families (YSS-F), the Youth Services Survey (YSS), and the Mental Health Services Improvement Program Survey (MHSIP). Collectively, these instruments are used to assess consumers' perceptions of quality and outcomes of care, and are currently being used for broad-based performance evaluation of California's community-based mental health services.

Data Sharing Challenges

Representatives of DMH were clear that, despite the obstacles, data sharing is an essential and desired development in the way their agency works with stakeholders—although constraints stemming from state budget limitations are a primary challenge when considering any data improvement or data sharing projects: The staff time and other resources required for data sharing and matching may not always be available.

The Medi-Cal billing system itself also presents challenges for sharing data. Counties may submit their billing information up to one year after service provision, with the resolution of those claims often taking an additional year from the time of submission. It is therefore possible to have data missing from the system for up to two years. This lag-time between services provided in the field and data collected at the state level could pose challenges for sharing and matching data with other departments. The lag-time is thought to result in particular inaccuracies when DMH attempts to demonstrate either prevalence of mental illness or penetration of services—both of which require the utilization of (often inaccurate or outdated) census numbers. Such inaccuracies lead to significant challenges in terms of the creation of meaningful projections, the demonstration of existing and future service needs, and the efficacy of DMH planning efforts.

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Another challenge is the variety of data systems used by California's many county mental health agencies. Nearly every county conducts its own data collection in a different way, with many variations in data reporting and no common identifier used across systems. Developing a system that can integrate this wide variation in systems is a sophisticated task that may be beyond DMH's current technological capabilities.

Another significant challenge for data sharing is HIPAA. Unlike CDSS, DMH is a covered entity and must comply with all HIPAA confidentiality regulations. This difference in status complicates the process of ensuring that shared data adheres to the appropriate level of HIPAA compliance. DMH representatives also indicated that there is variation in familiarity with and knowledge about HIPAA regulations throughout all levels of government. Data sharing is limited by this legislation, but the specific parameters of these limitations are not well known in the field. Nevertheless, the CDSS-DMH MOU permits data sharing within the constraints of HIPAA.

Data Sharing Activities and Benefits

Current Data Sharing Projects

As already mentioned, DMH has an MOU with CDSS. The purpose of this MOU is to provide access to confidential data for program monitoring and health oversight of children receiving child welfare services [in accordance with HIPAA Code 45 CFR 164.512(d) and to comply with the Mental Health Services Act of 2004, Proposition 63]. The MOU permits CDSS to receive DMH data concerning types of services provided, service dates, and diagnoses so as to examine how long children are in the child welfare system before receiving mental health services; DMH can receive CDSS information regarding the type and number of child welfare services received and expected costs of such services. Each department can request additional information for special study purposes. On an "as needed" basis, CDSS can provide a list of identifying information and relevant data fields for linking between the DMH Client and Services Information System (CSI) data, the Specialty Mental Health Medi-Cal data, the DMH Performance Outcome data, and the CWS/CMS of CDSS. The term of the MOU is May 1, 2007 to April 30, 2010.

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Potential Benefits to Data Sharing

In addition to their confirmed interest in data sharing with CDSS, representatives from DMH indicated a general interest in matching data with DOJ and CDCR. SAMSHA is interested in arrests that relate to mental illness, and DMH is similarly interested in the relations between justice and mental health statistics. Of particular concern is the transition from correctional facilities to community mental health treatment programs. Other states connect the data between these two systems, but California currently does not. DMH representatives felt that data sharing may help increase the success of clients' crucial transitions from the correctional system to the mental health system, and vice versa.

Interest in data sharing with ADP was also discussed with DMH representatives, as DCR data consistently reflect a high percentage of individuals with dual mental health and substance abuse diagnoses. Indeed, a movement toward the integration of these systems has reached the national level, as the effective rendering of services to these individuals would clearly be enhanced by data sharing between the departments that address both types of need.

Future Data Sharing Projects

Representatives from DMH mentioned a national movement toward the possible use of Electronic Health Records (EHR) to improve information exchange across agencies. This technology would allow key data factors to be collected about any child who receives health care. This would create a primary and consistent source for data, minimize stigmatization, and link publicly administered programs to data about individuals who may need their services. The Mental Health Services Act of 2004, Proposition 63, requires that local mental health service systems funded by the act consider EHR while building their data collection infrastructure. Therefore, the expectation clearly is that all mental health data collection systems will eventually be compatible with EHR. Although current discussions of EHR are taking place largely at the federal level, DMH representatives indicated an interest in data collection and sharing along this line.

Finally, DMH is co-sponsoring a grant proposal to the National Institute of Mental Health (NIMH) that would allow DMH to share de-identified data with the University of California, Berkeley. This

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grant proposal was submitted in response to an NIMH call for state agencies and partnering researchers to study the impact of changes in mental health policies (e.g., implementing parity), changes in delivery systems (e.g., introducing quality improvement initiatives, implementing managed behavioral health care in public systems), financial policy changes (e.g., implementing patient cost sharing), or other new or changed policies on the cost, quality of care, and outcomes for persons with mental disorders. If funded, the study will use existing de-identified administrative data to generate new information that can assist state mental health policy-making.

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CALIFORNIA ADMINISTRATIVE OFFICE OF THE COURTS

Dependency Courts, which are a part of the Superior Courts in California, hear cases about minors who may have experienced abuse or neglect (Sagatun & Edwards, 1995; Quas, Cooper, & Wandrey, in press). The Dependency Court plays a crucial role in the child welfare system, especially for those children who become wards of the court. The Judicial Council and the Administrative Office of the Court (AOC) set and help implement important policies for the Dependency Courts.

In general, the Judicial Council is the policymaking body of the California courts. The 27-member Council ensures consistent, independent, impartial, and accessible administration of justice. The Judicial Council is responsible for:

- Establishing direction and setting priorities for continual improvement of the court system;
- Promulgating rules of court administration, practice, and procedure;
- Sponsoring and taking positions on legislation that affects the California judicial system;
- Allocating the California judicial branch budget; and
- Responding to mandates from the Legislature.

The AOC is the staff agency to the Judicial Council and is responsible for a variety of programs and services to improve access to a fair and impartial judicial system. The agency is organized into 10 divisions in San Francisco, one division in Sacramento, and three regional offices (Southern, Northern/Central, and Bay Area/Northern Coastal).

The division of AOC that is of particular interest to the current project is the Center for Families, Children, & the Courts (CFCC), whose mission is to improve the quality of services to families, children, and self-represented litigants in the California courts. Many of CFCC's projects relate to family, juvenile, child support, custody, visitation, and domestic violence law and procedure. The Center also initiates projects involving issues of juvenile dependency, victim reconciliation, and court access.

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Purpose and Goals

On October 22, 2008, a meeting took place between CPPR staff and representatives from AOC. Attendees from each agency were as follows:

Administrative Office of the Courts

Christopher Wu, Supervising Attorney
Karen Cannata, Supervising Research Analyst (via telephone)
Sonya Tafoya, Senior Research Analyst
Chantal Sampogna, Attorney

Center for Public Policy Research

Gail S. Goodman, Director/Principal Investigator
Michael J. Lawler, Co-Director/Co-Principal Investigator
Shay K. O'Brien, Senior Writer
Christin Ogle, Research Analyst

The primary purpose of this meeting was for CPPR to follow up on the previous CDSS SIT investigation into data systems relevant to the AB 636 child well-being indicators used by CDSS in the course of their annual, federally mandated CFSR.

Attendees of this meeting explored further data sharing possibilities and discussed the potential benefits of linking statewide data systems. CPPR's goals for this meeting were as follows:

- To update information on AOC data systems as originally summarized in a CPPR report entitled, *Interagency Measurement of Child Well-Being*, dated December 2006.
- To obtain information about current data sharing practices and standards.
- To identify barriers (e.g., confidentiality, privacy) to information sharing across agencies.
- To assess data integration and shared data management possibilities between AOC and CDSS.
- To delineate potential benefits of sharing data for AOC, their stakeholders, and other departments and agencies across the state.

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Overview of Findings

AOC and CDSS are currently working together as partners with the goal of exchanging information within allowed parameters. The California Case Management System (CCMS) is a planned statewide technology for achieving a unified case management system for court cases, including for family and juvenile cases. The hope is to deploy the CCMS by 2012. Once the CCMS system becomes operational, the AOC and CDSS expect to develop MOUs or other formal agreements regarding data sharing. In addition, the AOC plans to formalize procedures for data integration with other partners.

Data Collection Practices and Projects

California Case Management System (CCMS)

In February of 2003, the Judicial Council approved the implementation of CCMS for all courts in California. The CCMS is a statewide technology initiative designed to achieve a unified case management system for the functions of civil, small claims, probate, mental health, criminal, traffic, family, and juvenile cases. AOC's Southern Regional Office in Burbank is coordinating the CCMS project, with the additional participation of the AOC Information Services Division and the Center for Families, Children, & the Courts in San Francisco.

Local court systems have historically administered their own data collection and management systems. However, variations in these systems often lead to significant communication and data sharing challenges, both across levels of the court system and across the state. In 2007, AOC began the process of developing the CCMS to integrate local court data systems into one statewide system. AOC plans to utilize a phased deployment process for the CCMS, with the database currently in design-phase only. The goal is to test the completed design by 2010 and to fully deploy the system by 2012.

The CCMS will be housed in the California Courts Technology Center (a central hosting site) to which each court will report uniform data. The CCMS will contain data from criminal, civil, and juvenile courts, as well as data related to court operations. In other words, the system will include applications for both cases and a variety of fiscal processes and administrative elements (see Appendix C).

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At heart, however, the CCMS is a case-based system that collects data at the individual level. In the juvenile court system, each child will be given a unique case number and personal identifier, which will then be linked with the child's family. By linking individuals to family units and connecting one family unit to another, CCMS will support the courts' efforts to manage families in a more unified, coordinated manner. This may reduce the number of hearings and lessen the risk of conflicting court orders.

The CCMS data will be supplemented at the case level by data collected in the CDSS CWS/CMS. The data collection burden on courts is greatly reduced by drawing performance measures from the child welfare outcome data already collected through this system. In addition, judges and other vital court officials will have access to information about the child and family on which to base decisions and make recommendations.

Juvenile Dependency Court Performance Measures Rule of Court

In 2004, a joint effort by the American Bar Association, the National Center for State Courts, and the National Council of Juvenile and Family Court Judges resulted in a publication entitled, *Building a Better Court: Measuring and Improving Court Performance and Judicial Workload in Child Abuse and Neglect Cases* (available online at www.ncsconline.org/wc/publications/res_ctpers_tcps_packgde4-04pub.pdf). This publication emphasized three important findings: The courts play a critical role in the safety, permanency, and well-being of abused and neglected children; improvement of court systems can improve outcomes for these children; and measuring performance is a vital element in this improvement effort.

The Pew Commission on Foster Care published a report in 2004 that recommended strategies for strengthening the court system. This report recommended that "[e]very dependency court should adopt court performance measures" and that "[s]tate judicial leadership should use these data to ensure accountability by every court for improved outcomes for children and to inform decisions about allocating resources across the court system." At that time, the Judicial Council accepted the Pew Commission's recommendations and began developing an implementation plan.

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At the recommendation of the Pew Commission, the Judicial Council formed The Blue Ribbon Commission on Children in Foster Care to provide leadership in the improvement of the courts and, ultimately, to protect children and pave their way toward placement permanency. In 2006, the California Legislature enacted AB 2216, which created Welfare and Institutions Code 16545 (available at <http://law.onecle.com/california/welfare/16545.html>). This code mandates that the Judicial Council adopt, through rules of court, those performance measures required by legislation. The adoption of these performance measures will allow the courts to track their own improvements related to children's safety, permanence, and well-being; to measure their own timeliness in addressing cases; and to inform decision-making about resource allocation.

Most relevant to the current report, Code 16545 also states that "performance measures shall be based on data that is available from current or planned data collection processes and, to the greatest extent possible, shall ensure uniformity of data reporting" (see Appendix D).

On October 24, 2008, representatives from AOC and Honorable Michael Nash (Presiding Juvenile Court Judge of the Los Angeles Dependency Court) proposed Rule of Court 5.505 to the Judicial Council for approval. Rule 5.505 outlines five categories of performance measures on which all California courts will be required to collect and submit data. Following the statewide implementation of CCMS, the courts will indeed be required to collect and submit data in all five categories outlined in Rule 5.505:

1. *Timeliness*—Data collected to expedite the placement of children into permanent families and track the efficiency of court processes.
2. *Court Procedures and Due Process*—Data used to track the fairness and thoroughness of court decisions. This segment also provides information for the general public regarding the actions and processes of the court system.
3. *Safety*—Data related to the safety indicators for children in foster care as outlined in AB 636. These measures will be produced with CWS/CMS data on safety and be accessible to the courts through an electronic link.
4. *Permanence*—Data regarding the placement of children into permanent family units. These measures will also be available to the courts electronically via CWS/CMS.

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5. *Well-being*—Data reflecting the child well-being measures related to placement with siblings, services for youth in transition to adulthood, and placement for Indian children. Additional measures in the areas of physical health, mental health, and education have been proposed. AOC will continue to conduct research, in collaboration with CDSS, to design and test these measures for future amendments.

A detailed summary of Rule 5.505 as well as a matrix of the data elements attending each of these performance measures is available online at www.courtinfo.ca.gov/jc/documents/reports/102408itemf.pdf. For the exact wording of Rule 5.505, see Appendix E.

Prior to the completion of CCMS, courts will be required to continue to collect and report data contained within their current data system. Rule 5.505 was supported unanimously by the Judicial Council and became effective as of January 1, 2009.

Data Sharing Challenges

Welfare and Institutions Code section 827 and California Rule of Court 5.552 regulate access to juvenile court files, limit viewing and distribution of all information within those files, and delineate the protocol to be used when data are requested from juvenile case files (Section 827 is available online at <http://law.onecle.com/california/welfare/827.html>, and Rule 5.552 is available at http://www.courtinfo.ca.gov/rules/index.cfm?title=five&linkid=rule5_552). Because these regulations limit access to data, they could pose significant challenges in any data sharing agreements.

HIPAA does not, however, seem to be a particular challenge for the courts in terms of data sharing: As courts are not covered entities, the confidentiality aspects of HIPAA do not apply. In addition, the Family Educational Rights and Privacy Act (FERPA) need not necessarily be an obstacle to data sharing practices, and representatives from AOC indicated that it is possible, in certain circumstances, to access and share data protected by FERPA. It should be noted, however, that the courts may not issue *standing orders* to receive protected information. Rather, courts may request specific information as needed on a case-by-case basis.

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Data Sharing Activities and Benefits

The ability to build a centralized database was made possible with the state funding of trial courts. The Trial Court Funding Act of 1997 (available online at info.sen.ca.gov/pub/97-98/bill/asm/ab_0201-0250/ab_233_bill_19971010_chaptered.pdf) provided courts with their first stable, secure, and highly accountable statewide funding system. Passage of this act centralized data systems and has allowed for the statewide data integration project (CCMS) under discussion.

Current Data Sharing Projects

The CCMS project requires improvement in data sharing activities between the courts and their various partner agencies through the application of standard data definitions and universal technology. Examples of the agencies identified for data exchange include:

- Appellate Court Case Management System (ACCMS),
- California Highway Patrol (CHP),
- California Department of Social Services (CDSS),
- Department of Child Support Services (DCSS),
- Department of Motor Vehicles (DMV),
- California Department of Justice (DOJ), and
- Local justice partners (e.g., prosecutors, public defenders, probation, sheriff)

For the past several years, CDSS has been actively involved in the development of the new database for AOC. The department has been instrumental in creating a set of high-priority data exchanges and will eventually review the final design documents for CCMS. Both AOC and CDSS have been working in tandem toward a shared goal of exchanging information within the allowed parameters. Contracted programmers are building current regulations and limitations into the system—a step that will allow the system to apply the appropriate rules and restrictions automatically depending upon the location and security level of the requester.

Potential Benefits to Data Sharing

The AOC representatives interviewed for this report identified the primary benefit of data sharing to be the potential improvement in the lives of at-risk children and their families. Ensuring that

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judges have complete and accurate information when making decisions is a substantial benefit to all those engaged in juvenile court.

There is also an administrative aspect to the benefits of data sharing, particularly once the CCMS is in place. For example, a social worker could enter initial contact data into the CDSS system, with those data then being available, in automated fashion, for the juvenile court petition. Shared data would also improve the AOC's capacity to measure court improvement in the areas identified within the rules of court, provide accurate and timely reports to both the public and the federal government, and thoroughly unify family court information.

Representatives from the AOC also noted that the data collected about families and individuals in the process of engaging in services such as education or medical treatment, already *belong* to those individuals. Representatives also clearly stated their belief that the best use for this information is to better serve those in the system. For courts to make informed decisions about the children and families they see, they must be up-to-date on the information collected—at the very least—by CDSS and CDE. In most cases and in specific courts (such as dependency drug courts), the importance of these data critically widens to involve, for example, ADP, DMH, and DHCS. In particular, the courts have no legal obligation to collect demographic information about the individuals they see; therefore, collecting demographic data from child welfare sources is an important part of providing judges with complete and accurate case information.

Future Data Sharing Projects

The Long-Range Strategic Plan for the California judicial branch, *Justice in Focus: The Strategic Plan for California's Judicial Branch, 2006-2012*, contains a detailed action plan for the Judicial Council's advisory committees and the AOC (available online at www.courtinfo.ca.gov/reference/documents/strategic_plan_2006-2012.pdf). The plan establishes mechanisms for the responsible management and fair administration of justice across the state while encouraging local management and discretion in court operations. In particular, this plan includes "modernization of management and administration" and "branch-wide infrastructure for service excellence." These two goals will be essential components of all developing and future data sharing endeavors.

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Throughout the CCMS design process, collaboration between CDSS and the AOC has been consistently positive. Once the system becomes operational, these partners will develop MOUs or other formal agreements regarding data sharing. The AOC will also formalize procedures for data integration between their agency and all justice partners.

In addition to the data sharing that is developing at the state level, counties will be arranging exchanges with their own local partners (e.g., a standard set of information to be exchanged between courts and local probation offices). The specifics of these arrangements, however, are still in development.

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CALIFORNIA DEPARTMENT OF EDUCATION

Children with a history of abuse or neglect perform more poorly than non-maltreated peers in school. For example, on average, they obtain lower standardized test scores and lower grades, they are more likely to repeat a grade and to be in special education classes, and they drop out of school more often (e.g., Fantuzzo & Perlman, 2007; Slade & Wissow, 2007). Moreover, they are disciplined more frequently while in school (e.g., Cicchetti & Toth, 2005). Contributing to these problems are the greater mobility, family instability, and attention problems that so hamper children involved in the child welfare system. In an attempt to improve children's chances of academic success, Assembly Bill 490 (Steinberg) imposed new duties and rights related to the education of dependents and wards in the child welfare system. For example, it authorized the release of foster youths' educational records to the county-level agency responsible for the placement, for purposes of compliance with case management responsibilities. Such data sharing potentially increases the chances for maltreated children to succeed in school. In addition, CDSS is required to report educational information to the federal and state government. Thus, sharing of educational information is a priority for a multitude of reasons.

The mission of CDE is to provide leadership, assistance, oversight, and resources so that all Californians, including those in the child welfare system, have access to an excellent education. CDE oversees the state's diverse and dynamic public school system that is responsible for the education of more than 7 million children and young adults in more than 9,000 schools. The State Superintendent of Public Instruction and CDE are responsible for enforcing education law and regulations, and for continuing to reform and improve public elementary school programs, secondary school programs, adult education, child care programs, and many preschool programs.

CDE is committed to working in partnership with local schools to improve student achievement. Its goals include:

1. Holding local educational agencies accountable for student achievement;
2. Building local capacity to enable all students to achieve state standards;

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3. Expanding and improving a system of recruiting, developing, and supporting teachers that instills excellence in every classroom;
4. Providing statewide leadership that promotes effective use of technology to improve teaching and learning;
5. Increasing efficiency and effectiveness in administration of kindergarten through Grade 12 education;
6. Providing broader and more effective communication among the home, school, district, county, and state;
7. Establishing and fostering systems of school, home, and community resources that provide the physical, emotional, and intellectual support that each student needs to succeed;
8. Advocating for additional resources and flexibility, and providing statewide leadership that promotes good business practices; and
9. Improving the effectiveness and efficiency of the Department.

Purpose and Goals

On November 17, 2008, a meeting took place between CPPR staff and representatives from CDE. Attendees from each agency were as follows:

Department of Education

Sonya Edwards, Education Administrator
Craig Pierini, Education Programs Assistant
Marsha Devine, Education Programs Consultant

Center for Public Policy Research

Gail S. Goodman, Director/Principal Investigator
Michael J. Lawler, Co-Director/Co-Principal Investigator
Shay K. O'Brien, Senior Writer
Ingrid M. Cordon, Quantitative Analyst

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The primary purpose of this meeting was for CPPR to follow-up on the previous CDSS SIT investigation into data systems relevant to the AB 636 child well-being indicators, as well as data used by CDSS in the course of their annual, federally mandated CFSR.

Attendees of this meeting explored further data sharing possibilities and discussed the potential benefits of linking statewide data systems. CPPR's goals for this meeting were as follows:

- To update information on CDE data systems (originally obtained by CPPR and summarized in the *Interagency Measurement of Child Well-Being* report, dated December 2006).
- To obtain information about current data sharing practices and standards.
- To identify barriers (e.g., confidentiality, privacy) to information sharing across agencies).
- To assess data integration and shared data management possibilities between CDE and CDSS.
- To delineate potential benefits of sharing data for CDE, their stakeholders, and other departments and agencies across the state.

Additional written feedback on the present chapter was provided by CDE subsequent to the draft version of this report submitted to the Data Linkage and Information Sharing Committee of the CWC in December 2008. This feedback has been incorporated into this chapter.

Overview of Findings

CDSS and CDE have discussed the establishment of an MOU for data sharing. An important consideration regarding the sharing of educational information is FERPA, which limits the education data that can be shared with state agencies. An authoritative legal interpretation of FERPA clarifying state and local educational data sharing rights and responsibilities would facilitate relevant data sharing across the state. In regard to datasets, the California Longitudinal Pupil Achievement System (CALPADS), soon to be in place, will include longitudinal, individual-level data (e.g., demographics, grade level, enrollment, discipline, state assessment, and other data required to meet state and federal reporting requirements), although special education data, housed in the California Special Education Management Information System (CASEMIS), will not be linked to CALPADS.

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Current Data Collection Practices and Projects

CDE manages approximately 125 data collections. The primary databases used and managed by CDE, as well as projected data systems, are described here. A list and description of other CDE databases is available online at: <http://inet2.cde.ca.gov/dataresourceguide/search.aspx>.

California Longitudinal Pupil Achievement System (CALPADS)

CALPADS is the foundation of California's K-12 education data system. This database contains both individual-level and aggregate-level data. When fully implemented in 2010, CALPADS will maintain longitudinal, individual-level data including information on student demographics, program participation, grade level, enrollment, course enrollment and completion, discipline, state assessment, teacher assignment, and other data required to meet state and federal reporting requirements. Data will be linked longitudinally using a unique, non-personally identifiable Statewide Student Identifier (SSID). Some community colleges are voluntarily incorporating the SSID into their enrollment process, which will allow CDE to track these students through at least part of their post-secondary education. However, at the time of this report, there are no firm plans to, or designated resources for, tracking students beyond the K-12 education system. At present, special education data from the California Special Education Management Information System (CASEMIS) is not expected to be linked to CALPADS. CALPADS implementation is projected to occur in 2009-10. Sample CALPADS data variables are listed in Appendix F.

California Longitudinal Teacher Information Data Education System (CALTIDES)

CALTIDES is a system that will integrate teacher credential and authorization data to CALPADS data. This database contains both individual-level and aggregate-level data. Data will be linked longitudinally using a unique, non-personally identifiable Statewide Educator Identifier (SEID). CALTIDES implementation is projected to occur in 2010-11.

California School Information Services (CSIS)

CSIS is a funded initiative that permits the transfer of student records electronically from participating school districts. This database contains both individual-level and aggregate-level data. The CSIS program is a statutorily authorized local educational entity with the mission to 1)

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build the capacity of local educational agencies (LEAs) to implement and maintain comparable, effective, and efficient student information systems that will support LEA daily program needs and promote the use of information for decision making by school, district, and county staff; 2) enable the accurate and timely exchange of student transcripts between LEAs and post secondary institutions; 3) assist LEAs to transmit state reports electronically to CDE, thereby reducing the reporting burden of LEA staff; and 4) assist LEAs to assign and maintain Statewide Student Identifiers (SSIDs).

California Basic Educational Data System (CBEDS)

CBEDS contains data about basic student and staff information, including data on student enrollment, graduates, dropouts, course enrollment, enrollment in alternative education, and gifted and talented education. This database contains aggregate-level data that are collected annually. CBEDS will be retired as CALPADS comes online.

Online Public Update for Schools (OPUS)

OPUS is a project to develop a web-based application for LEA aggregate-data reporting at the school and district levels. CDE's vision is to reduce the number of LEA data collections over time. The non-student data in the CBEDS and selected other data collections have been judged to be more efficiently reported in aggregate form in a single application, such as OPUS. Certain data elements (e.g., counts of students enrolled in opportunity schools) may be migrated to OPUS when CBEDS is retired. The first phase of the OPUS project began in October of 2008.

California Special Education Management Information System (CASEMIS)

CASEMIS is an information reporting and retrieval system regarding special education, developed by the CDE Special Education Division. This database contains both individual-level and aggregate-level data. The system has been designed to assist LEAs, special education local plan areas (SELPAs), county offices of education, school districts, and state-operated programs for the disabled (SOP) submit student-level data to CDE. CASEMIS includes data on 1) students referred and evaluated for special education services; 2) services received; 3) disciplinary actions; and 4) post-secondary follow-up.

California Department of Social Services and Child Welfare Council Data Linkages Project

DataQuest

DataQuest is a dynamic relational public information system that provides summary reports, including reports on accountability (e.g., Academic Performance Index, Adequate Yearly Progress), test data, enrollment, graduates, dropouts, course enrollments, staffing, and data regarding English learners. Data are available at several levels of aggregation (e.g., state, county, district, school).

Data Sharing Challenges

CDE representatives indicated that FERPA limits the education data that can be shared with other state agencies. Furthermore, FERPA is not interpreted consistently across districts, which may complicate local data sharing efforts. CDE representatives indicated that an authoritative legal interpretation of FERPA that clarifies state and local data sharing rights and responsibilities could help mitigate some of the problems arising from differing interpretations of FERPA across the state.

Existing protocols for access to child welfare services data at the local level also require refinement and standardization. Foster care liaisons across school districts report varying levels of access to child welfare services data, from limited to no access. Training and uniformity of access at the local level would allow service providers to identify and provide appropriate services to students in the child welfare system.

Local capacity for data management affects the accuracy of some of the data obtained by CDE. Funding for district training on data management best practices is necessary, in part, to affirm the usefulness and importance of the data (e.g., district-level summary reports, enrollment by subgroups), particularly if data tracking for children in the welfare system is enhanced. Moreover, improving processes that already exist, such as determining who has educational rights, would improve the district's ability to provide educational services.

Data Sharing Activities and Benefits

CDE representatives expressed a willingness to provide information and share data with partner agencies (e.g., CDSS) to support state needs as possible. This willingness to share data is

California Department of Social Services and Child Welfare Council Data Linkages Project

predicated on evaluation of each project for suitability, existence of a federal law exempting applicable FERPA regulations, receipt of a list of students for whom data would be matched, availability of resources to support the effort, and the existence of an established MOU.

Currently, CDE has an MOU in place to share data with CDSS for the Direct Certification Program, as required by the US Department of Agriculture. The program provides for the direct certification of low-income students, which enables students to enroll in the Free and Reduced Lunch program. The certification process requires the matching of student enrollment data with Food Stamp Program and CalWORKs recipient data. This data sharing process is made possible by an exception to FERPA regulations outlined in federal law. A similar law related to foster care or provision of social services would need to outline federal permission for CDE to share data with CDSS or any other state agency.

Another possibility for navigating the restrictions within FERPA is to include a consent process whereby the person with educational rights to make decisions regarding a student involved in the child welfare system could authorize the sharing of that student's data. Such consent would need to be properly documented according to FERPA requirements and would allow sharing of data not otherwise possible.

In addition to federally mandated reporting and data matching procedures, data sharing with sister agencies would assist CDE in better identifying the needs and backgrounds of its students, particularly those students in the child welfare system, and in providing the educational services necessary to meet student needs. Early identification of students involved in the child welfare system, along with their educational history, would also help school districts provide the appropriate educational services to these at-risk students as quickly as possible.

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Data Linkages Project

CALIFORNIA DEPARTMENT OF HEALTH CARE SERVICES

Children in the child welfare system are among the most vulnerable children in the country. Nearly 40 percent of these children are born with low birthweight and/or prematurely, two factors that increase the likelihood of medical problems in childhood (Kicker, Gordon, & Knitzer, 2001). Moreover, maltreatment places individuals at risk of health problems as adults (Felitti et al., 1998; Schneider et al., in press). Interventions to prevent and treat health problems can benefit from data sharing.

DHCS is responsible for administering the Medi-Cal program, as well as the programs within the Children's Medical Services Branch. It also maintains all Medi-Cal data. Its data are especially germane to CDSS, as DHCS houses the majority of state information on children's issues. For example, it oversees the mandatory reporting of child welfare data, data which are subsequently sent to the federal government. DHCS also houses data for the estimated 75,000 California children in foster care.

The mission of DHCS is to protect and improve the health of all Californians. To this end, DHCS works closely with health care professionals, county governments, and health plans to provide a health care safety net for people with low incomes and people with disabilities who meet defined eligibility requirements. The department also helps maintain the financial viability of critical specialized care services, such as burn centers, trauma centers, and children's specialty hospitals. In addition, DHCS funding helps hospitals and clinics located in underserved areas and those serving underserved populations. DHCS also provides health care services to low-income individuals and families, the elderly, people with specific diseases, and children with special medical needs.

The health care programs overseen by DHCS provide low-income families, children, pregnant women, seniors, and persons with disabilities access to critical health care. Most of the DHCS budget is allocated to the provision of benefits under the Medi-Cal Program, which provides health care services to welfare recipients and other qualified low-income persons (primarily families with children and the aged, blind, or disabled).

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Purpose and Goals

On November 5, 2008, a meeting took place between the CPPR staff and representatives from DHCS. Attendees from each agency were as follows:

Department of Health Care Services

Marian Dalsey, Chief, Children's Medical Services Branch

Jane Lamborn, Office of Legal Services

Luis Rico, Chief, Systems of Care Division

Jim Watkins, Chief, Medical Health Care Statistics Section, Fiscal Forecasting
and Data Management Branch

Center for Public Policy Research

Michael J. Lawler, Co-Director/Co-Principal Investigator

Ce Ce Iandoli, Research Manager

Ingrid Cordon, Quantitative Analyst

Shay K. O'Brien, Senior Writer

The primary purpose of this meeting was for CPPR to follow up on the previous CDSS SIT investigation into data systems relevant to the AB 636 child well-being indicators used by CDSS in the course of their annual, federally mandated CFSR.

Attendees of this meeting explored further data sharing possibilities and discussed the potential benefits of linking statewide data systems. CPPR's goals for this meeting were as follows:

- To update information on DHCS data holdings since its separation from what was formerly known as the Department of Health Services. When the report entitled *Interagency Measurement of Child Well-Being* was completed by CPPR in 2006, both DHCS and CDPH were one agency.
- To obtain information about current data sharing practices and standards.
- To identify barriers (e.g., confidentiality, privacy) to information sharing across agencies.

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- To assess data integration and shared data management possibilities between DHCS and CDSS.
- To delineate potential benefits of sharing data for DHCS, their stakeholders, and other departments and agencies across the state.

Additional written feedback was provided by DHCS subsequent to the draft version of this report submitted to the Data Linkage and Information Sharing Committee of the CWC in December 2008. This feedback has been incorporated into the current report.

Overview of Findings

Since its inception in July of 2007 as an independent department (upon the separation of the Department of Health Services into DHCS and CDPH), DHCS has operated a centralized data warehouse developed by Bull Services (purchased by Ingenix) and Business Objects (in concert with Teradata software). This warehouse provides policy-makers and government agencies access to large scale datasets, as well as specific data elements. The DHCS data warehouse rapidly provides a broad range of health care program data, and—given that Ingenix’s primary target audience is state and local governments—comparable systems are already in use at both the Michigan and Minnesota Departments of Human Services.

Current Data Collection Practices and Projects

DHCS houses several databases of considerable interest to the present report. See Appendix G for information on DHCS data bases and variables.

One particularly large and important database is the Medi-Cal Eligibility Data System, commonly known as “MEDS.” Because special education and regional center clients, among many other clients, are served through Medi-Cal, HIPPA and FERPA laws may apply to MEDS data.

An example of especially relevant DHCS data derives from their Child Health and Disability Prevention (CHDP) Program. This program delivers periodic health assessments and services to low income children and youth in California. CHDP collects data that are reported to DHCS on its PM-160 form. This form is submitted for any child, including those in the child welfare

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system, receiving a CHDP Health Assessment. These data are used for payment if the child is in a fee-for-service Medi-Cal program and to annually report summary data to Federal Centers for Medicare and Medicaid Services on all children receiving CHDP services, including those children in Medi-Cal managed care plans. The results of a CHDP Health Assessment, including the findings of the exams and need for referrals to other services, are documented at the time of the visit and a copy of the PM-160 is given to the foster parent at the time of the health assessment. However, statutes and regulations prohibit the sharing of patient-specific data unless informed consent is granted.

Also of special interest for the present report is DHCS' centralized data warehouse, and specifically how it operates, given its potential as a model for data warehouses more generally. The first step in the DHCS data warehousing process begins with the collection of each agency's data. At DHCS, the Information Technology Services Division (ITSD) collects the data, standardizes the information into Extended Binary Coded Decimal Interchange Code (EBCDIC) files, and transfers those files to the centralized server of the Management Information System/Decision Support System (MIS/DSS) in the data warehouse.

The DHCS MIS/DSS subsequently converts those EDCDIC files into relational data via an accessible common identifier. DHCS relies on a client identifier number (or CIN, which is unique to Medi-Cal programs) as its common identifier rather than using client social security numbers (SSN). SSNs are still used, however, for data matching and probabilistic sampling with various databases. For example, DHCS houses data regarding medical services (abstracted from a submitted claim for payment) for children in foster care throughout the state. Therefore, it is possible that entities interested in a child's services could enter his/her social security number into the system. Using commercial-off-the-shelf (COTS) software, the DHCS MIS/DSS can explore available data fields within the database that supply information about benefits and services provided to a given foster child.

Use of this system has some particular considerations:

- Given the apparent ease of access to this information, security has been heightened and access has become more delineated. Surveillance of the sources of the data and the

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utilization of the data is reported regularly. Currently, there are five levels of access to the data (from total access to all fields and tables to only de-identified data from the data warehouse).

- Data are in the department's format and stored at the record level. Business rules can be applied to the system when developing filters or views for the user community and can be updated easily. Business rules can also be applied by the user in development of report specifications.
- Data are available from January 1, 1998, and can be pulled by record, provider, or by beneficiary.

As of November 5, 2008, DHCS's data warehouse holds over 10 years of data on eligibility and claims. The warehouse has information on over 18 million eligible people across all DHCS programs for the 10-year timeframe and over 3 billion claim lines.

DHCS Performance Measures

DHCS has developed a template for county departments to use for assessment of their performance [i.e., Quarterly Progress Report Template: Outreach, Enrollment, Retention, Utilization (OERU) and Evaluation]. These performance measures include assessment of: outreach to eligible California citizens, enrollment in the appropriate programs, retention in programs, and utilization of services. The data are subsequently used to compile DHCS reports. The performance measures contained in the OERU include: 1) the number of children and families reached and assisted by Medi-Cal, 2) completed applications, 3) the number of children enrolled in the Healthy Families program, 4) the number of families assisted with an annual eligibility review, and 5) the number of families and children utilizing services as a result of the assistance they received through DHCS. See Appendix H for OERU forms.

Data Sharing Challenges

DHCS' primary barriers to data sharing with other departments and agencies are as follows:

- State and federal laws bar the disclosure of individual-identifying data except under limited circumstances and may be a barrier to the disclosure of data by DHCS to other departments and agencies.

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- Federal laws such as FERPA further complicate the dispersal of information.
- Medicaid law bars the release of information from the Medi-Cal program other than for purposes directly related to the administration of the Medi-Cal program, which may limit the amount of data sharing that can be achieved.
- Medi-Cal service providers may not accurately report the services provided. For example, a provider may rely on the phrase "group counseling" for a number of services that may not, in fact, fit all definitions of group counseling sessions. One permissible phrase used in reporting service utilization may refer to a wide variety of mental health services, which can potentially diminish the specificity of data collected.
- Since its separation from CDPH, DHCS has lost access to data held by the Office of Statewide Health Planning and Development (OSHPD). The information now held by OSHPD contains more detail about in-patient care, vital statistics, and birth-related data—data that have historically been used in tandem with data now managed by DHCS. Ultimately, the annual Medi-Cal Funded Deliverables Report is impossible to produce without access to these data sources.
- Entities and individuals are often reticent to share data due to fears of taking on responsibility for protected information. Data sharing also requires a thorough understanding of the rules of the agencies: what they can or cannot share; the ways they transfer data; and their capacity for protecting data, encrypting transmissions, and securing electronic lines. Medi-Cal business rules comprise a full 800 pages of text, and the possible consequences of security breaches or data loss quite often prove daunting.

Data Sharing Activities and Benefits

Current Data Sharing Projects

DHCS is currently in the process of assessing strategies for once again gaining access to OSHPD data.

DHCS shares information by dispensing data, cross-matching data, de-identifying those data, and then transferring the information (typically via CD-ROM) to the requestor. Recently, DHCS created a new process for reviewing applications from researchers for the release of data for use in research projects and for public health purposes. This process established a Data

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Research Committee at DHCS to review applications and to execute data use agreements with the researchers for approved projects. See Appendix I for further information.

Potential Benefits to Data Sharing

As possible, DHCS is highly amenable to data sharing with DDS—and, in fact, is currently doing so in an informal manner. However, federal FERPA regulations forbid any *formal* data sharing between the agencies. There may be a number of special education students eligible for special education and medical care who are not currently being served. DHCS would like to centralize all those data so as to better serve eligible students in this population.

Future Data Sharing Projects

After interviewing members of DHCS, CPPR's research team deemed the agency a potential model of best practices. Its databases are already centralized; are convertible from flat files into relational ones; and are capable of probabilistic matching, data conversion into a common language, and the rapid analysis of outcomes. As a result of its interoperability features, its capacity to produce meaningful, broad-based reportage is superb. In May of 2008, for example, DHCS provided an overview of the foster care population reported within Medi-Cal programs (information gleaned from Short-Doyle Forms) from 2000 to 2006. The report tied together six years worth of data on children in foster care from mental health diagnoses to the use of psycho-therapeutic medications. The results of this study were delivered by Sandra Shewry (the Director of Health Care Services at that time) to the CWC on April 14, 2008 and are available online at: [http://www.chhs.ca.gov/initiatives/CACChildWelfareCouncil /Documents/CWCHHealthCoverage41008.ppt](http://www.chhs.ca.gov/initiatives/CACChildWelfareCouncil/Documents/CWCHHealthCoverage41008.ppt).

To realize the possibility of a statewide interagency data sharing enterprise, DHCS suggested two possible options that could be explored:

1. Form a new research committee, and
2. Consider using an outside research entity—possibly a UC campus—to work on an interagency data sharing project. Researchers are also subject to state law and HIPAA constraints, and DHCS opposes any arrangement that would circumvent those constraints.

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CALIFORNIA DEPARTMENT OF PUBLIC HEALTH

Children and families who come into state custody often engage in behavior that is risky to their health—such as smoking and overeating (e.g., Schneider et al., in press). Moreover, child abuse can increase the risk of exposure to and spreading of contagious diseases or unwanted health conditions (e.g., Thomas, Hypponen, & Power, 2008; Wilson & Widom, in press). Data sharing between CDSS and public health agencies could enhance the state's ability to promote healthy lifestyles and prevent disease among children and their families involved in the child welfare system.

CDPH is dedicated to optimizing the health and well-being of the people in California. It offers an array of services primarily centered on:

- Promoting healthy lifestyles for individuals and families in their communities and workplaces.
- Preventing disease, disability, premature death, and reducing or eliminating health disparities.
- Protecting the public from unhealthy and unsafe environments.
- Providing or ensuring access to quality, population-based, health services.
- Preparing for, and responding to, public health emergencies.
- Producing and disseminating data to inform and evaluate public health status, strategies, and programs

CDPH oversees the delivery of these services directly or through partnerships with experts who monitor community health problems, offer information to enhance people's health, and generate innovative solutions to public health problems.

Purpose and Goals

On September 22, 2008, a meeting took place between the CPPR staff and representatives from CDPH. Attendees from each agency were as follows:



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Department of Public Health

Linette Scott, Deputy Director, Health Information and Strategic Planning Division

Tony Agurto, Chief of the Center for Health Statistics (CHS)

Jane McKendry, Chief of Office of Health Information and Research

Scott Fujimoto, Office of Health Information and Research

Center for Public Policy Research

Mary Tran, External Consultant, CPPR

Gail Goodman, Director, Principal Investigator, CPPR

Ce Ce Iandoli, Research Manager, CPPR

CPPR requested a second meeting to talk with several staff members about the current status of the data sharing process among the units of CDPH. This second meeting took place on October 27, 2008. Public Health staff spoke with CPPR staff via a conference call. The following staff members were present:

Department of Public Health

Tony Agurto, Chief of the Center for Health Statistics (CHS)

David Fisher, Chief of Informational Technology Services Section (within CHS)

Jane McKendry, Chief of Office of Health Information and Research

Scott Fujimoto, Office of Health Information and Research

Center for Public Policy Research

Gail S. Goodman, Director/Principal Investigator

Michael Lawler, Co-Director/Co-Principal Investigator

Ce Ce Iandoli, Research Manager

Only personnel from Health Information and Strategic Planning Division (HISP) were interviewed for this report, but it should be noted that many other divisions within CDPH (Infectious Disease; Maternal, Child and Adolescent Health; Environmental Health; etc.) collect and sometimes share data as well. In future investigations, these divisions should be included to provide a more complete picture of CDPH.

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The primary purpose of both meetings was for CPPR to follow-up on the previous CDSS SIT investigation into data systems relevant to the AB 636 child well-being indicators, as well as data used by CDSS in the course of their annual, federally mandated CFSR.

Attendees of this meeting explored further data sharing possibilities and discussed the potential benefits of linking statewide data systems. CPPR's goals for this meeting follow:

- To update information on CDPH's data holdings since its separation from what was formerly known as the Department of Health Services. When the report entitled, *Interagency Measurement of Child Well-Being* was completed in 2006, both CDPH and DHCS were one agency.
- To obtain information about current data sharing practices and standards.
- To identify barriers (e.g., confidentiality, privacy) to information sharing across agencies.
- To assess data integration and shared data management possibilities between CDPH and CDSS.
- To delineate potential benefits of sharing data for CDPH, their stakeholders, and other departments and agencies across the state.

Additional written feedback was provided by the Office of Health Information and Research subsequent to the draft version of this report submitted to the Data Linkage and Information Sharing Committee of the CWC in December 2008. That feedback has been incorporated into the current report.

Overview of Findings

Each CDPH dataset has its own laws and guidelines restricting access, and each database may include several subsets of data with different restrictions. Each program also handles its own data: Typically two to three people become experts on the rules guiding each data set. Currently, CDPH has more than 100 data sets serving 300 programs. All databases contain individual-level data.

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CHS's data are derived from vital records, which are entirely reliant on the facts given by someone at the junction of a key life event (e.g., birth, death). CHS does not independently verify the information that individuals provide, although amendments can be filed to correct previous errors. The formal restrictions imposed on these data are expressed in statute. The information is also subject to state and federal guidelines that are separate from HIPAA requirements.

CDPH has a process in place for sharing data between departments. At the onset of the project, a committee is formed with a representative from each department as well as personnel able to address the mutual needs, available resources, and applicable regulations and restrictions. The committee outlines the costs of the project. The committee's decisions are written into an Interagency Agreement (IA).

Vital statistics databases are available to external researchers on CD-ROMs. As part of this process, researchers submit an application justifying their need for the data, the type of data needed (e.g., identifiable versus de-identified data), and a signed agreement not to forward the data to third parties or use it for purposes other than stated in the application. Data requests for research purposes must be approved by the Committee for the Protection of Human Subjects and the Vital Statistics Protection and Advisory Committee. CHS personnel then provide CDs with the information researchers formally requested.

Current Data Collection Practices and Projects

CHS (within CDPH) data consist mainly of legal certificates for births and deaths of individuals, which are submitted by county registrars. These data differ from data collected by most other state departments because they are derived from legal documents. Birth and death certificates are legal mandates and have long been primary sources of public health data.

CDPH houses a variety of other documents besides birth and death certificates, including documents related to:

- Information relevant to diseases and environmental health,
- Guidelines for healthy living,

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- Consumer information,
- Patients' rights and workplace safety,
- Certificates and licenses for occupations in health-related fields, and
- Certificates verifying that certain conditions do not pose health hazards.

CDPH also offers access to public records predicated on the Public Records Act. An online procedure for accessing these records is available at: <http://www.cdph.ca.gov/Pages/PublicRecords.aspx>. However, the public may not view confidential records.

The department also offers statistical information on a variety of databases, answers data queries, writes reports, and brokers questions related to its core mission. A public website is also available, which defines and describes diseases, outlines programs and services, and includes links to fact sheets and further resources on a range of health conditions. See Appendix J for data variables relevant to CDPH.

Data Sharing Challenges

Although there are more than 100 data sources within CDPH, there is no consolidation of data into a central repository. One researcher from CHS noted, "We don't see ourselves as a central distribution point for data files. Very specific laws guide the distribution of CDPH's data. For example, the Health and Safety Code has been developed at various points throughout the years, and therefore multiple statutes govern the use of data.

Representatives indicated that CDPH would be unwilling to share data if they had reason to believe they would subsequently lose control of that data, particularly because components of the agency house extensive and complicated datasets, acting as stewards guided by statutes and the specific regulations attached to stewardship.

Other data challenges were also mentioned, including:

- Data linkages could compromise the confidentiality of the original data.
- If a data sharing agreement could be reached that adequately addressed other issues, sufficient staff might not exist to conduct the necessary merges.

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- The data collected by CDPH is often derived from legal forms (e.g., birth certificates), which are not designed for, nor easily adaptable to, specific research questions.
- An IA might be required to share the data, which can be a complex process.

Data Sharing Arrangements and Benefits

Current Data Sharing Projects:

Representatives from CHS outlined the necessary steps for the creation of a data sharing agreement:

1. Conduct preliminary talks with another Department about the project.
2. Form a committee from both Departments to outline mutual data needs, available resources, applicable regulations/restrictions, and costs.
3. Formalize the resulting scope of work in an IA.
4. Move the IA into the contractual process.

OSHPD has the only existing agreement with CHS that permits re-release of linked data. For example, OSHPD has a contractor who links both birth and death data to OSHPD data. Because OSHPD's confidentiality is stricter than CDPH's requirements, and restrictions are specified in the IA, CDPH trusts this process. OSHPD also creates quarterly reports on which files, data elements, or agency documents have been exchanged. CHS does not authorize anyone else to re-release or distribute its files.

Future Data Sharing Projects:

In potential data sharing arrangements with other departments, CHS would be interested in frequent updates with longitudinal data. A representative suggested that it might be useful to incorporate other data sources into morbidity and county health status reports.

Staff members would also like to know more about the quality of the data they would receive, such as:

- What is included?
- What are the potential uses of the data?
- How usable are the data?

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- Is the documentation sufficient?
- Are the data available in SAS or other formats used within CDPH?
- How would they be delivered?
- Where would data be stored?

CDPH also offered these suggestions about how to make interagency sharing possible:

- Create a Health Information Exchange Group
- Develop a standardized IA, which must have rules about how data are transferred.
- Share data of equivalent value in lieu of paying money for access.
- Use the strictest confidentiality agreements of all the datasets shared.
- Link data with Geographic Information Systems (GIS)

In December 2008, CDPH began to explore modifications in data management to improve programs. A potential project the agency may consider is setting up the infrastructure necessary to make data accessible (via server) to staff within each department—and, ultimately, to the entire agency.

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CALIFORNIA DEPARTMENT OF ALCOHOL AND DRUG PROGRAMS

With what seems to be increasing frequency, children in California are entering foster care because their parents are addicted to alcohol or drugs. Moreover, many infants are born to mothers who abused alcohol or drugs while pregnant; these infants are candidates for being placed immediately in protective custody. A sizeable number of children in foster care whose families were torn apart by substance abuse will go on subsequently to abuse alcohol or drugs themselves (e.g., Vaughn, Ollie, McMillen, Curtis, Scott, & Munson, 2007; Widom & Hiller-Sturmhofel, 2001). A connection between child maltreatment, on the one hand, and alcohol and drug abuse, on the other hand, is clear. In this regard, coordinated case management should encompass both adults' (e.g., parents') and children's (e.g., teenagers') alcohol and drug abuse programs along with child welfare services programs.

ADP is responsible for administering and coordinating the State's efforts in alcohol and drug abuse prevention, treatment, and recovery services. ADP is also the primary state agency responsible for interagency coordination of these services.

In partnership with California's 58 county alcohol and drug program administrators—and in cooperation with numerous individuals, organizations, and agencies (both public and private)—ADP provides leadership and coordination in the planning, development, implementation, and evaluation of a comprehensive statewide alcohol and drug use prevention, intervention, detoxification, treatment, and recovery system. The Department utilizes each of the 58 county alcohol and drug programs as the broker of these services. ADP also contracts directly with "Direct Contract Providers." The counties, in turn, are able to provide services to clients either directly or by contracting with local service providers. California employs a statewide treatment, recovery, and prevention network of over 850 public and private community-based service providers, serving approximately 300,000 clients annually.

Purpose and Goals

On October 8, 2008, a meeting took place between CPPR staff and representatives from ADP. Attendees from each agency were as follows:

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Department of Alcohol and Drug Programs

George Lembi, Manager of Research

Tom Leigh, Research Program Specialist I

Center for Public Policy Research

Gail S. Goodman, Director/Principal Investigator

Michael J. Lawler, Co-Director/Co-Principal Investigator

CeCe Iandoli, Research Manager

Shay K. O'Brien, Senior Writer

The primary purpose of this meeting was for CPPR to follow up on the previous CDSS SIT investigation into data systems relevant to the AB 636 child well-being indicators used by CDSS in the course of their annual, federally mandated CFSR.

Attendees of this meeting explored further data sharing possibilities and discussed the potential benefits of linking statewide data systems. CPPR's goals for this meeting were as follows:

- To update information on ADP data systems as originally summarized in a CPPR report entitled *Interagency Measurement of Child Well-Being*, dated December 2006.
- To obtain information about current data sharing practices and standards.
- To identify barriers (e.g., confidentiality, privacy) to information sharing across agencies.
- To assess data integration and shared data management possibilities between ADP and CDSS.
- To delineate potential benefits of sharing data for ADP and their stakeholders as well as other departments and agencies across the state.

Overview of Findings

Data concerning alcohol and drug programs fall under especially stringent confidentiality and privacy laws, quite likely the most stringent of any department or agency covered in this report. Particular attention to these laws will need to be paid in any data sharing agreement between CDSS and ADP. Fortunately, representatives of ADP indicated that data sharing could be

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possible if an appropriate linkage system that adequately protected privacy and confidentiality were in place.

Subsequent to the data sharing analysis conducted by CPPR in 2006, ADP shifted from reliance on the California Alcohol and Drug Data Set (CADDs) to use of the California Outcomes Measurement System (CalOMS). This more comprehensive database (launched in January 2006) includes the data elements from CADDs and adds a set of 24 outcome measures. ADP representatives indicated that CalOMS is working well and provides ADP with comprehensive client demographics, as well as critical post-treatment information in the form of outcome-based data. Although the vast majority of ADP's data relate to their adult clientele (approximately 92% of the individuals served by ADP are adults), the high percentage of child-welfare-services families who are in drug and alcohol abuse programs makes clear the need for coordination of services between ADP and CDSS.

Current Data Collection Practices and Projects

The California Outcomes Measurement System (CalOMS)

The California Outcomes Measurement System (CalOMS) is a statewide client-based data collection process and its associated database. In January of 2006, this system replaced ADP's previous database—CADDs—which had been in use for the previous 15 years. CalOMS is designed to allow ADP to effectively manage and improve the provision of alcohol and other drug services at the state, county, and provider levels, and specifically permits ADP to track outcome data for people who receive treatment.

CalOMS is a unified dataset that serves multiple purposes at both the state and federal levels of government. CalOMS data are collected and organized via five identifiable elements:

1. Unique Client Identifier (UCI): The UCI is a set of 13 data elements related to personal/demographic client information. This information is critical in that it enables ADP to track individuals as they move through systems of care. This information is used to identify the spectrum of treatment services a given person receives during a treatment episode.

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2. Treatment Episode Data Set (TEDS): The TEDS is a set of federally required data elements pertaining to client admission and discharge. Admission and discharge data on all clients served in California's publicly funded treatment programs must be reported via TEDS.
3. California Alcohol and Drug Data Set (CADDs): This is the system ADP built in 1991 to collect TEDS required data. The elements of the CADDs data set include all the required TEDS elements, optional TEDS elements used for state reporting, and state-required data elements. CADDs/TEDS questions have been included in the CalOMS data set to provide a more seamless collection of required data.
4. National Outcome Measures (NOM): The NOM dataset evolved from the Performance Partnership Grants (PPG) system—itsself a set of data elements proposed by the federal Center for Substance Abuse Treatment (CSAT)—and is designed to measure outcomes. PPG data were to have been reported by states annually in concordance with proposed changes to federal fund allocation via the Substance Abuse Prevention and Treatment (SAPT) block grant. However, as the CSAT continued to work with states in developing the PPG, the proposed PPG evolved into the NOM. Currently, the NOM dataset includes outcome measures that will continue to be reported in the State's annual SAPT block grant application. These data elements allow for the assessment of changes in a number of life areas, including: alcohol/drug use, employment and education, criminal justice involvement, family and living conditions, access and capacity, social connectedness, and retention/length of stay at treatment facilities. As a number of these life areas are still being defined by CSAT, only some of the proposed measures will be collected during Phase 1 of CalOMS implementation.
5. Minimum Treatment Outcome Questions (MTOQ): The MTOQ dataset consists of 30 data elements and was developed by ADP in collaboration with the Treatment Sub Work Group of the Implementation Working Group (IWG). Like the NOM, the MTOQ question set was designed to measure outcomes in a number of life areas. More specifically, MTOQ data enable the measurement of change in seven domains: alcohol use, drug use, employment, family/social networks, medical services, legal issues, and psychological health.

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CalOMS data are required from all providers licensed for Narcotic Replacement Therapy, as well as from all providers receiving public funding (even if that funding is for a single client). An exemption to this rule exists for providers who receive funds exclusively through the Substance Abuse Crime Prevention Act (SACPA), with such providers only having to collect and report CalOMS data on clients funded by SACPA monies. Outcome data are collected at admission and discharge at each type of treatment level. Treatment service providers who do not receive public funding do not report data to ADP.

CalOMS data are delivered to ADP monthly in batch files from counties and, in some cases, from direct providers. Files are then uploaded into the CalOMS system. CalOMS contains 13 variables related to personal identification, including standard demographic variables (first and last name, gender, date of birth, race/ethnicity), as well as social security number. These variables are used to match client records via a probabilistic algorithm. Information on matched clients is added to the client's existing file, and new clients are entered into the system under a unique identifier. As of October 2008, CalOMS includes roughly 85 data elements, which are available through an online data dictionary at <http://www.adp.ca.gov/CalOMS/CalOMSmain.shtml>.

ADP's treatment data are collected at the individual level and stored in flat (vs. relational) files for analysis using SAS statistical software. ADP also collects some amount of aggregate-level data related to the many prevention (as opposed to treatment) activities that take place throughout the state.

See Appendix K for a list of ADP data variables.

Data Sharing Challenges

ADP's primary barriers to data sharing are 1) HIPAA, and 2) existing mandates for the protection of confidentiality outlined in Code of Federal Regulations 42, Part 2 (available at http://ecfr.gpoaccess.gov/cgi/t/text/text-idx?c=ecfr&tpl=/ecfrbrowse/Title42/42cfr2_main_02.tpl), which specifically addresses protections for alcohol and drug abuse patient records. Regulations enforcing confidentiality are more stringent for substance abuse data than for data

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related to other services. ADP, therefore, has historically only permitted uni-directional data sharing—that is, the entry of data into their system for matching to their own client information. Few options exist for ADP data to be sent the other direction (i.e., outward for use by other entities). Additional data sharing challenges noted by ADP representatives were lack of a standardized data structure, limited staff and technological resources, and the lengthy process required to navigate the State’s Institutional Review Board (IRB).

Approaches for Overcoming Barriers

Data experts at ADP indicated that there are several successful approaches and strategies taken by their department to overcome barriers to data sharing:

- Work with requestors to limit public health information (PHI) data elements to a minimum necessary.
- Provide aggregated data rather than client-level data when possible; de-identify records if client-level data are necessary.
- Mask small cell sizes in aggregated reporting.
- Roll up counties with populations under 20,000 into a composite unit.
- Use standard business associate agreements covering privacy and confidentiality mandates for entities receiving PHI (see Appendix L).
- Collaborate and consult with the Committee for the Protection of Human Subjects and research entities in processing IRB applications.
- Review concerns about confidentiality and privacy with the ADP departmental HIPAA units. (Departmental policies and procedures were revised to be in compliance with federal HIPAA mandates.)
- Consult with in-house legal counsel on matters of privacy and confidentiality.

Data Sharing Activities and Benefits

Current Data Sharing Projects

At the time of this report, ADP shares data with the University of California, Los Angeles (UCLA) to evaluate the SACPA program. This partnership allows UCLA to conduct cost/benefit analyses for the services provided by SACPA. UCLA receives the client data set for this program and

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matches it with corrections and employment data. The cost/benefit analysis then facilitates examination of the fiscal impact of client outcomes (e.g., return to prison, employment) after participation in the SACPA. This data sharing agreement is a mandatory feature of the SACPA legislation, which requires external evaluation of the program.

ADP is also in the process of developing an MOU with the Rand Corporation to examine the effects of financial decisions on individuals receiving substance abuse treatment. This MOU will lay the groundwork for other potential data sharing agreements.

Potential Benefits to Data Sharing

In the course of the current investigation, broad benefits of data sharing were discussed. ADP representatives indicated that there are clear benefits to sharing data with other agencies. They noted that significant amounts of data about people in substance abuse *treatment* exist, but relatively little information is available about the prevalence of the problem of alcohol and other drug use throughout the state. Representatives from ADP suggested that access to information on the *prevalence* of alcohol and drug problems (as opposed to information only on the number of people receiving treatment) could greatly benefit the agency. These data could be used in both statewide planning and in ADP's reporting to executive staff. Solving confidentiality issues would foster more efficient and consistent reporting between agencies and would also benefit ADP.

Thus, sharing information across agencies may increase knowledge about the prevalence of substance abuse throughout the state. ADP staff representatives believe that a well-rounded picture of the State's substance abuse efforts could be aided by access to data gathered by other major agencies such as the Departments of Corrections and Rehabilitation, Social Services, Employment Development, Education, and Mental Health.

Information about young peoples' involvement with alcohol and other drugs also represents a serious gap in the data available to ADP. Data and documentation from other state agencies, departments, and programs could help fill some of this gap, particularly in understanding the scope of need for youth services. Increased access to data would allow ADP to demonstrate the

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existence of these gaps and then to advocate for increased attention to this underserved population.

There is a possible benefit in sharing data with CDSS in the area of Medi-Cal. ADP dispenses Medi-Cal payments for drug-related health care, and billing data may prove useful if shared across agencies.

ADP reports a vast array of data in the annual block grant application submitted to the Center for Substance Abuse Treatment (CSAT). This block grant application includes information about goals and objectives, clients, programs, expenditures, the prevalence of alcohol and other drugs use, treatment effectiveness, and incidence of related conditions (i.e., AIDS, hepatitis, and tuberculosis). The importation of CDSS data would be helpful in providing a more comprehensive picture of the client population, as well as of program effectiveness.

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CALIFORNIA DEPARTMENT OF CORRECTIONS AND REHABILITATION

A particularly negative outcome experienced by many youth who exit foster or group care is incarceration—initially in juvenile institutions and later in adult prisons. Research confirms a “cycle of violence” wherein people who were abused and neglected in childhood are more likely than those who were not to become involved in criminal behavior, including violent crime, later in life (Aceves & Cookston, 2007; Fang & Corso, 2007; Widom, 1989). Moreover, children first placed in foster or group care between the ages of 12 and 15, and children with multiple placements and multiple spells in care are at a particularly high risk of incarceration for a serious or violent offense even during adolescence (Johnson-Reid & Barth, 2000). Given the nexus that exists between child maltreatment, out-of-home care, delinquency, and adult criminality, it is incumbent on the state to do what it can to break this cycle of violence.

The overarching mission of CDCR is to protect the public from crime and victimization through the safe and secure incarceration of offenders, effective parole supervision, and rehabilitative strategies designed to successfully integrate offenders back into the community.

There are many Divisions within CDCR, but ones of particular note here are the Division of Juvenile Justice (DJJ), which is charged with treatment, training, and education of some of the most challenging juveniles in the state; the Division of Addiction and Recovery Services (DARS), which primarily serves inmates with substance abuse problems; and the Enterprise Information Services (EIS), which provides IT organization and technological innovation and leadership. The recent *Plata v. Schwarzenegger* lawsuit resulted in the creation of two new divisions within CDCR, namely the Division of Correctional Health Care Services and the California Prison Health Care Services. In June of 2005, federal courts established a receivership covering the medical services of these divisions.

Currently, CDCR operates 33 adult institutions statewide, which are categorized under varying security levels ranging from the less secure Level 1 (open dormitories without a secure

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perimeter) to the most secure Level IV (fenced cells or walled perimeters, electronic security, enriched staffing, and armed officers both inside and outside the installation).

CDCR also operates 6 juvenile institutions and 15 regional juvenile parole offices. As part of the State's criminal justice system, DJJ works closely with law enforcement, the courts, district attorneys, public defenders, probation, and a broad spectrum of public and private agencies concerned with and involved in tracking and aiding the youth who receive treatment, training, rehabilitation, and education in DJJ facilities.

Additionally, CDCR's Conservation Camp Program consists of 46 adult and 2 DJJ conservation camps statewide. CDCR also jointly manages numerous adult and juvenile camps with the California Department of Forestry and Fire Protection (CAL FIRE). These partnership crews perform a vital public service benefiting Californians as well as state, federal, county, and local government agencies. Over 4,400 adult offenders are currently in the program—fighting wildfires, responding to floods and earthquakes, and conducting search and rescue missions. CDCR also operates 13 community correctional facilities and 7 out-of-state correctional facilities (designed to temporarily alleviate overcrowding within existing institutions).

After their institutional stay, inmates and youths are paroled into their communities. The mission of the Division of Adult Parole Operations and the Division of Juvenile Parole Services (within DJJ) is to protect the public and assist parolees in their reintegration into society, with parole offices for both adult and juvenile operations being located throughout the state.

Purpose and Goals

On November 6, 2008, a meeting took place between CPPR staff and representatives from CDCR. Attendees from each agency were as follows:

Department of Corrections and Rehabilitation

Steven Chapman, Assistant Secretary Office of Research

Paula Agostini, Chief, Adult Research Branch

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Bernard Warner, Chief Deputy Secretary, Division of Juvenile Justice, Child Welfare Council Member

Bob Eden, Senior Programmer, Supervisor Ward Information Network

Eleanor Silva, Acting Administrator, Division of Juvenile Justice

Sandra Youngen, Director, Division of Juvenile Programs

Cathi Negri, Staff Services Manager, Information Systems Unit

Amy Seidlitz, Division of Juvenile Justice Reform Team

Robie Sweet, Adult Research Branch

Shiyloh Duncan, Juvenile Research Branch

Dominc Hatfield, Information Systems Unit

Ed LaCroix, Enterprise Information Systems

Susan Eastwood, Performance Based Standards

Center for Public Policy Research

Gail S. Goodman, Director/Principal Investigator

Michael J. Lawler, Co-Director/Co-Principal Investigator

Shay K. O'Brien, Senior Writer

Ingrid M. Cordon, Quantitative Analyst

The primary purpose of this meeting was for CPPR to follow up on the previous CDSS SIT investigation into data systems relevant to the AB 636 child well-being indicators used by CDSS in the course of their annual, federally mandated CFSR.

Attendees of this meeting explored further data sharing possibilities and discussed the potential benefits of linking statewide data systems. CPPR's goals for this meeting were as follows:

- To identify and describe existing and proposed CDCR data systems.
- To obtain information about current data sharing practices and standards.
- To identify barriers (e.g., confidentiality, privacy) to information sharing across agencies.
- To assess data integration and shared data management possibilities between CDCR and CDSS.

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- To delineate potential benefits of sharing data for CDCR, their stakeholders, and other departments and agencies across the state.

Overview of Findings

CDCR representatives indicated strong interest in data sharing to meet state needs. Data sharing would benefit CDCR's program and planning efforts. Information on juvenile backgrounds (e.g., maltreatment, mental health, education, disabilities) would lead to better understanding of offenders' needs. However, HIPAA and FERPA are relevant to possible data sharing agreements. Offenders, especially juvenile offenders, are considered "protected populations"; thus, data sharing practices may be particularly restrictive for them.

Current Data Collection Practices and Projects

The following are descriptions of the primary adult and juvenile databases used and/or managed by CDCR's Office of Research, with the names of data variables (where available) listed in Appendix M. All databases contain individual-level data. Aggregate-level information can be obtained from the following databases as needed.

Adult Data Systems

Offender Based Information System (OBIS)

OBIS is an offender data management system that serves as the Department's official source of offender information to external entities. The OBIS system houses information on offenders throughout their time in the correctional system from commitment to final discharge.

Distributed Data Processing System (DDPS)

Hewlett Packard minicomputers form this system, which connects all 33 state prisons and central office functions using applications that track inmate movements and housing, inmate classification levels, monies and restitution fines, tuberculosis test results, visitors and inmate visits, and canteen and inventory sales.

Inmate Classification Scoring System (ICSS)

This database contains information regarding an inmate's risk classification, which is assessed through the Classification Score Sheet (form 839) when an inmate is first committed. The classification score is a critical piece of information because it is used to: 1) identify the potential

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risks that the inmate poses to himself or herself and others; 2) determine the security level of the inmate's housing; and 3) categorize the prison population in ways that may drive decision making.

Offender Information Services Branch Data Warehouse (OISB DW)

The DW contains information from the OBIS database. The DW includes derived values (such as the Inmate's Life Number) and other useful data relations that do not exist in the OBIS itself. Data are 'filtered' using business rules, and computed variables are added.

CalParole Tracking System (CalParole)

This multi-user system captures, stores, and manages information relating to inmates paroled from state prison.

Parole Revocation Hearing Tracking System (RTS)

This system provides information on all parolees who are under a CDCR hold or until a revocation decision by the Board of Prison Terms is finalized. A record is created for each CDC parolee arrested and is maintained and updated in the RTS active database until the board decision is finalized, at which time the record is transferred and stored.

Parolee at Large Recovery Tracking System (PALRTS)

This system contains information concerning the identification, location, and activities that lead to the apprehension of parolees at large.

Juvenile Data Systems

Offender-Based Information Tracking System (OBITS)

OBITS is a legacy mainframe system written in ADABASE, Natural, COBOL, and Construct, and is widely regarded as being the "system of record" for data related to wards' commitment, movements, and calculation of Available Confinement Time (ACT).

Ward Information Network (WIN)

WIN contains information related to youths' stays in DJJ facilities, including demographic information, movements, treatment information, and educational history. The WIN system is a custom application built specifically to cover the policies and practices of the DJJ (formerly the California Youth Authority). WIN has been in production and in constant development since 1991. It was created at one facility and became the standard for DJJ institutions by 1996. The architecture takes into consideration the daily operations of all staff.

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Young Offender Database Application (YODA)

This application is utilized for complete parolee data, from the receipt of the request for parole plans through parole and discharge. It includes information on address, phone numbers, registrations, detentions, warrants, board appearances, time history, registrations, parole conditions, report due dates, unit rosters, agent assignments, and INS status. It also includes OBITS information.

Field Information System (FIS)

This system is accessed and updated by the field parole agents using a handheld "notebook." The FIS system replaces the paper process previously utilized by agents in the field.

Violence Risk Classification Database (VRC)

This database contains information regarding a youth's risk classification.

Sex Offender Referral Classification Database (SORD)

This database contains information on a youth's sexual offending risk. A Sexual Offender Referral Document (SORD) is completed at the Reception Center and Clinic. It is also completed when wards disclose non-documented sexual offenses, commit new sexual offenses, or develop a pattern of deviant sexual behavior.

Treatment Need Assessment Database (TNA)

This database contains information concerning a ward's treatment needs (mental health, substance abuse) and treatment planning.

Future Direction

Strategic Offender Management System (SOMS)

SOMS is CDCR's planned effort to put its organization on a current technological platform and footing. The SOMS project is an opportunity for CDCR to implement the assessment, treatment, and follow-up programs that were recommended by the CDCR Expert Panel in its 2007 Report to the California State Legislature on reducing recidivism and increasing public safety. To implement these processes and to evaluate their effectiveness, CDCR will need to collect data about each ward, inmate, and parolee's participation in these programs, as well as on the extent of their participation. Data may be needed to support the administration of individualized treatment plans in a case-management setting and to monitor how well the programs themselves have been implemented.

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Data Sharing Challenges

CDCR representatives indicated that both HIPPA and FERPA are regulations that are highly relevant to data sharing restrictions. Offenders, particularly juvenile offenders, are considered protected populations and thus data sharing practices may be particularly restrictive for these populations. CDCR representatives also indicated that confidentiality issues and regulations may differ from county to county. Additionally, information for juveniles whose cases are sealed would not be accessible for sharing.

The reliability and accuracy of information across datasets varies, and data systems differ considerably from county to county. Moreover, a reliable common identifier is not yet available across datasets. Other considerations with regard to data sharing concern the need to protect victims and their rights to privacy, the protection of co-defendant confidentiality, and the establishment of levels of data accessibility.

Data Sharing Activities and Benefits

CDCR representatives indicated a strong willingness to provide information and share data with sister agencies to support state needs. Currently, CDCR has a data sharing agreement to receive the arrest history for adult inmates and parolees from the DOJ to conduct automated risk assessments through an MOU with DOJ. CDCR is also developing an MOU with the California Law Enforcement Training System. In addition, the State Privacy Officer is currently convening work groups to assess and facilitate data sharing among agencies.

Sharing data would also greatly benefit CDCR program and planning efforts. Obtaining information about juvenile backgrounds (e.g., maltreatment history, mental health, education, disabilities) would assist CDCR in better understanding the needs of offenders. In particular, data sharing would aid CDCR in carrying out assessment, case management, treatment provision, and juvenile re-entry and transition activities. Thus, sharing information with other state agencies, such as the Departments of Education and Mental Health, would be beneficial to the individuals CDCR serves and would greatly assist CDCR in meeting its mission and responsibilities. Representatives also felt data sharing would be highly beneficial in gathering

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information about children in the child welfare system and in developing programs for female offenders.

As part of their SOMS data system development, CDCR identified several state databases from which they would like to obtain data, including: CDSS, the Judicial Council of California, the Federal Bureau of Justice Statistics and Parole Database, the Criminal Justice Information System, California Law Enforcement, the Information Telecom System, the Department of Justice Database, the Discharge Offender Record Management System, the California Department of Motor Vehicles, the Felony Complaint Report and Filing Information, the Los Angeles County Probation Database, Minute Orders, the National Law Enforcement Information Telecom System, the Probation Officer's Report, the Report of Arrest and Prosecution, the Social Security Administration, and the California Department of Veterans Affairs.

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CALIFORNIA DEPARTMENT OF DEVELOPMENTAL SERVICES

Children in the welfare system are at high risk of developmental delays. Research reveals, for example, that over half of the young children in foster care experience developmental delays (e.g., language delays), which is four to five times the rate found among children in the general population (Dicker et al., 2001). Many children in the welfare system are born at low-birth weight or premature, which can lead to developmental disabilities. In addition, children with disabilities are at increased risk of experiencing child maltreatment (Sullivan & Knutson, 2000).

DDS provides services and support to individuals with developmental disabilities—for example, mental retardation, cerebral palsy, epilepsy, autism, and related conditions. Services are provided through state-operated developmental centers and contracted nonprofit regional centers. DDS operates five such developmental centers, located in San Jose, Costa Mesa, Pomona, Porterville, and Eldridge (Sonoma County), as well as two smaller state-operated community facilities in Yuba City and in Cathedral City. These facilities provide an array of services and supports for individuals in need of a secure environment and/or those who have special medical and/or behavioral program needs. Providing 24-hour services, these facilities deal with all facets of the individuals' lives, including skills training, specialized health care and other therapies, and leisure and recreational opportunities. The primary aims of the developmental centers are to provide services designed to increase residents' levels of independence and functioning skills, their ability to control their environment, and their ability to live in community settings.

Additionally, DDS contracts with 21 nonprofit regional centers that serve as local resources to assist individuals with developmental disabilities in accessing services and supports. These regional centers provide diagnosis and eligibility assessments, and then assist in the planning, coordinating, and monitoring of the services and supports that are most needed. Many of the regional center services are provided for free, regardless of age or income, and include the following: information and referral; assessment and diagnosis; counseling; individualized planning and service coordination; advocacy for the protection of legal, civil, and service rights;

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early intervention services for at-risk infants and their families; family support; and community education about developmental disabilities.

Purpose and Goals

On October 15, 2008, a meeting took place between CPPR staff and representatives from DDS. Attendees from each agency were as follows:

Department of Developmental Services

Marjorie Mar Liu, Programmer Analyst/Data Extraction

Sue Boucher, Manager, Training and Data Services

Center for Public Policy Research

Gail S. Goodman, CPPR Director/Principal Investigator

Michael J. Lawler, CPPR Co-Principal Investigator

Shay O'Brien, Senior Writer

Ingrid Cordon, Quantitative Analyst

The primary purpose of this meeting was for CPPR to follow up on the previous CDSS SIT investigation into data systems relevant to the AB 636 child well-being indicators used by CDSS in the course of their annual, federally mandated CFSR.

Attendees of this meeting explored further data sharing possibilities and discussed the potential benefits of linking statewide data systems. CPPR's goals for this meeting were as follows:

- To update information on DDS data systems (originally obtained by CPPR and summarized in the Interagency Measurement of Child Well-Being report, dated December 2006).
- To obtain information about current data sharing practices and standards.
- To assess data integration and shared data management possibilities between DDS and CDSS.
- To identify barriers (e.g., confidentiality, privacy) to information sharing across agencies.

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- To delineate potential benefits of sharing data for DDS, their stakeholders, and other departments and agencies across the state.

Overview of Findings

The Lanterman Developmental Disabilities Services Act and HIPAA provide federal and state regulations, respectively, that are relevant for DDS's ability to share data with other agencies. However, provisions in both HIPAA and the Lanterman Act provide exceptions that may permit DDS data sharing with other state agencies. Moreover, DDS participates in the California Privacy and Security Advisory Board (CalPSAB), established by the California HHSA to address and coordinate health information exchange (HIE) in California.

Current Data Collection Practices and Activities

The primary data resources maintained by DDS were the same as those identified by CPPR in the 2006 report, namely:

- Purchase of Service System (POS),
- Vendor System (Vendor),
- Client Master File (CMF),
- Client Development Evaluation System Report (CDER), and
- Early Start Report System (ESR).

See Appendix N for a list of variables contained in these datasets. Archives from each system are extracted on a monthly basis and maintained on a mainframe at the Department of Technology Services. The full archive database contains 625 data elements and includes over 60 million records. All systems are linked by a Unique Client Identifier (UCI), with the exception of the Vendor System, which is linked to the POS by the Vendor ID. Longitudinal data can be extracted using monthly archives, and many cohorts of clients are followed over time (e.g., autism cases). The Data Extraction Unit at DDS extracts, maintains, analyzes, and develops reports from these database systems. Additionally the Data Integrity Unit monitors DDS datasets for errors and makes corrections when necessary. Data are available in SAS format, although DDS can convert datasets into other formats as needed (e.g., Excel, Access). All

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databases contain individual-level data, although data in each of the databases can be aggregated as needed.

Data matching with other state systems can be accomplished by utilizing various data elements within the CMF system—including, for instance, client's name, date of birth, gender, social security number, and address. Data matching with POS, CDER, and ESR archives can be accomplished by utilizing the UCI, which can be obtained from the CMF archives. The exception to the utilization of UCI for data matching is the Vendor system, which uses a vendor ID. However, the vendor ID is linked to the POS system, which can be matched to the UCI identifier.

Purchase of Service System (POS)

The POS archives include information on all services provided to clients and on all service claims filed since 1987. This database contains individual-level data. The POS uses both the UCI and Vendor ID as identifiers. The POS database contains 10 variables, and no recent changes to this system were reported.

Vendor System (Vendor)

The Vendor archives track vendor information for all DDS service providers. This database contains individual-level data. The Vendor system uses the Vendor ID as an identifier, which is linked to the POS database. The Vendor archive contains 18 variables, and recent changes to the Vendor system were reported.

Client Master File (CMF)

The CMF archives contain information on all persons served by DDS. This database contains individual-level data. The file is extracted and archived monthly from June 1992 forward. CMF files are updated as needed, with most clients contacted on a yearly basis. The CMF system utilizes the UCI as an identifier, although other demographic information is available for data matching purposes. CMF contains 86 variables, and no recent changes to the CMF system were reported.

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Client Development Evaluation Report (CDER)

The CDER system contains information on diagnostic, developmental, and behavioral assessments for all active service recipients over the age of three years. This database contains individual-level data. Reports are updated yearly for most clients and tri-annually for others. The CDER system utilizes the UCI as the primary identifier, although other demographic information is available for matching purposes if necessary. CDER contains 203 variables. The original CDER system has been revised, and the revised system has been in use since January 2008.

Early Start Reporting System (ESR)

The ESR system contains information on diagnostic, developmental, and behavioral assessment information on all active service recipients under the age of three years. ERS archives are updated at least yearly. This database contains individual-level data. ESR archives use the UCI as the primary identifier, although other demographic information is available for matching purposes. The current ESR system contains 198 variables, but it is currently in the process of being revised.

Data Sharing Challenges

DDS representatives indicated that HIPAA and the Lanterman Developmental Disabilities Services Act (California Welfare and Institutions Code §4400 et seq., available at <http://www.dds.ca.gov/Statutes/LantermanAct.cfm>) provide federal and state regulations relevant to data sharing with other agencies. The Lanterman Act, put into practice in 1977, defines the rights of persons with developmental disabilities and establishes how services to individuals with developmental disabilities will be delivered. Section 4514 of the Lanterman Act sets limits on information sharing, stating that “all information and records obtained in the course of providing intake, assessment, and services under Division 4.1 (commencing with Section 4400), Division 4.5 (commencing with Section 4500), Division 6 (commencing with Section 6000), or Division 7 (commencing with Section 7100) to persons with developmental disabilities shall be confidential. Information and records obtained in the course of providing similar services to either voluntary or involuntary recipients prior to 1969 shall also be confidential.” However, provisions in both HIPAA and the Lanterman Act provide exceptions that may permit data sharing with other state agencies and individual researchers. DDS representatives

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indicated that legal representatives participate in the California Privacy and Security Advisory Board (CalPSAB). CalPSAB was established by the California HHSA to provide private and public collaboration to address and coordinate health information exchange (HIE) privacy and security efforts in California.

Workload considerations also constrain DDS data sharing capacities. Although their data extraction staff does an excellent job of meeting external requests for data, staff resources are limited, and thus internal data requests must take priority.

Data Sharing Activities and Benefits

DDS representatives expressed a strong willingness to provide information and share data with sister agencies to support state needs. Data sharing and other reports are requested from DDS for issues relating to, for example, cost containment, budgeting, state and federal reporting, auditing, identification of clients with co-occurring disorders, tracking service trends, and market research. Currently, DDS has an MOU with CDSS for the purpose of monitoring and analyzing program information and outcomes pertaining to children and youth who are receiving services from both departments (see Appendix O). In addition, DDS has MOUs in place to share data with the Adoptive Assistance Program at CDSS, the Environmental Health Investigations Branch at CDPH, the Newborn Hearing Screening Program at DHCS, and the Tax Support Division at EDD. DDS is in the process of developing an MOU with CDCR for the Wards with Disabilities Program, and an additional MOU with the CDHCS Medical Services component to support the DDS Independent Risk Assessment and Mitigation Services project.

DDS representatives are interested in participating in a broader data sharing venture with other state agencies to eliminate barriers and streamline processes that currently obstruct data sharing efforts. DDS representatives indicated that legislative mandates and programmatic and cost containment issues generally serve as an impetus for broader data sharing efforts.

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STATE BEST PRACTICES

As part of the current project, CDSS requested a summary of data sharing arrangements, obstacles, and best practices from other states that could prove useful in the development of California's current effort toward data sharing. Indeed, a number of states have been rigorously pursuing this goal since the late 1990s. Others have only recently begun to take serious steps toward the legislative, infrastructure, and funding changes necessary to effect measurable change in data sharing practices.

Particularly thorough and persuasive case studies of state data sharing practices have been conducted by the Data Quality Campaign (DQC), a collaborative effort between the National Center for Educational Achievement (NCEA) and 13 other managing partners. The goal of the DQC is to encourage and support the implementation of high-quality, longitudinal data systems. With the NCEA as a founding member, the focus of the DQC is educational data—or, more specifically, the improved collection, availability, and utilization of high-quality educational data. Their overarching goal is to support state efforts to move away from cohort analysis and toward child-focused data practices that allow both schools and state governments to provide individualized services to every student and, ultimately, to improve educational achievement. Despite their focus on education, much in general can be learned from their analysis.

The various state-level case studies produced by the DQC stemmed from site visits, interviews, and investigations undertaken in the spring of 2006 with state education agencies (SEAs) in four states, including Florida and Utah. The resulting state reports were written with the goal of highlighting best practices, compiling lessons learned, and helping researchers and state governments avoid duplicative efforts.

The following begins with distillations of information from the DQC's case study of Florida and Utah. Again, while the focus of the reports is longitudinal data systems that support *educational* achievement, the overall theme of "high-quality, individualized data to help children succeed" extends well beyond school systems and SEAs, instead involving a variety of agencies whose missions include the health and well-being of children. Lessons learned across Departments of

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Education and Social Services, for example, can clearly be adapted to state agencies involved in criminal justice, juvenile justice, public health, social welfare, and the like. The State Best Practices section of this report then closes with a description of Colorado's cross-agency data sharing efforts. These efforts specifically concern the courts and Colorado's Department of Human Services.

Florida

The state of Florida has long been recognized as a leader in the data sharing movement, based largely on the activities of the Florida Department of Education (FLDOE). This leadership role has resulted from both the strength and consistency of their organizational efforts toward data sharing, as well as tangible achievements in the form of organizational change, database creation, and the day-to-day utilization of the long-range data sharing systems.

The cornerstone of Florida's data sharing efforts has been, quite simply, the FLDOE's creation of a single organization responsible for its major student-focused databases. This organization—The FLDOE Division of Accountability, Research, and Measurement—is responsible not only for both the operation and maintenance of key databases, but also, perhaps far more crucially, for the maintenance of key data exchange relationships. As defined in the DQC's 2006 case study on the FLDOE, the key functions that fall under this category of "relationship maintenance" include:

- The creation of specified collection cycles,
- The creation of standardized data element definitions,
- The establishment of delineated security and exchange protocols, and
- The coordination of all access protocols, research efforts, and reporting activities related to the involved datasets.

To provide an idea of the scope of this task, a sampling of the disparate organizations with which the division is successfully working includes:

- The Florida Board of Governors,
- Independent Colleges and Universities of Florida,
- The Department of Children and Families,

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- The Agency for Workforce Innovation,
- The Department of Juvenile Justice,
- The Department of Corrections, and
- The Department of Vocational Rehabilitation.

The Division of Accountability, Research, and Measurement also maintains functional data exchange relationships with a number of national-level data sources, including the National Student Clearinghouse, the College Board, ACT, the Federal Employment Data Exchange System, and the Wage Record Interchange System. Once again, the DQC credits the achievement of such a mammoth task with the FLDOE's consistent focus on the provision of organizational leadership and structure, the protection of student privacy (seen as a guiding principle rather than an impediment), and the clear and consistent definition of the *purposes* of data exchange.

Detailed Dataset Examples

Two core data systems established and maintained by the FLDOE are its PK20 Education Data Warehouse and The Florida Education and Training Placement Information Program (FETPIP).

The PK20 Education Data Warehouse was initially developed and populated through a vendor contract that ran from early 2001 to the spring of 2003. The initial goals of setting up the warehouse were to integrate 26 state-level data systems and provide the state a view across its K-12 educational environment. Personally identifiable data were never stored in the warehouse, with individuals being tracked over time via a randomly generated unique identification number. Since its establishment, the warehouse has grown and operated in the following manner:

- Data from existing sources are loaded into the warehouse based on a common set of business rules and data definitions;
- Only educational data warehouse staff have access to the warehouse database;
- Reports are both internally generated and externally requested (and can be produced with relative ease and speed); and

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- Any request for detailed-level data from outside departments must pass through an extensive approval process before any data release occurs.

The second highlighted data system, the FETPIP, is an interagency collection process that was begun in 1984 with the goal of consistently and systematically gathering follow-up data on all former students, including data on employment, military enlistment, incarceration, public assistance participation, and continuing education. This is accomplished by electronically linking data from the PK20 Education Data Warehouse to data records maintained by other state and federal agencies.

Implementation Processes

Florida's achievement of these advanced levels of data exchange have been predicated on strong legislative support in the form of long-range planning, state statutes, and early influxes of funds via state budgeting allotments. That said, the process was also somewhat incremental in that the first few years of the state's efforts (i.e., efforts towards the establishment of the current system) involved intermediate steps. For example, a system known as the Florida Information Resource Network

(FIRN) allowed districts to electronically submit data that were, at the time, being collected disparately and locally. This first step was later bolstered by the establishment of the FETPIP, which incorporated the collection of follow-up information on students who had exited the P-12 system. Only after this and several other incremental steps did the data warehouse itself become possible.

The following are examples of types of data in the data warehouse:

- **Student** — demographic, enrollment, educational programs, promotion, attendance, test scores, other characteristics
- **Child welfare** — children in foster care
- **Educational institution** — types, location, graduation rates
- **Financial aid** — state/local, loans/grants, disbursement
- **Student employment** — industry, military, wages
- **Courses** — offerings, student and teacher participation, instruction type, grades
- **Educational staff** — demographic, certification, instruction type
- **Educational finance** — budget and expenditures to the school level

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In addition to incremental implementation and early legislative support, other lessons highlighted in the DQC's case study include Florida's ongoing commitment to:

- Conduct annual data conferences designed to inform district staff of changes and updates.
- Conduct semi-annual meetings of an association of Management Information System (MIS) staff designed to share knowledge and impart lessons learned.
- Define, process, and implement new legislative mandates in a way that will prove least burdensome on school districts.

Benefits and Uses

The first lesson to take from Florida is the lesson of success. In other words, the data sharing system maintained by the FLDOE is not only working, it is realizing increasing levels of efficiency and effectiveness, and is conveying numerous benefits to the state, its school districts, and its student body. The DQC summarizes these benefits in terms of:

- Increases in accuracy and efficiencies in data collection over time.
- The efficiencies inherent in state department efforts to define elements such as course numbers so that districts do not have to develop these. Standardization allows information to transfer from district to district and to higher education with shared understanding of how elements are defined.
- The state's growing capability to cross reference data files submitted by the districts and identify errors and anomalies.
- The FLDOE's ability to provide data to federal offices (such as the Office for Civil Rights) instead of having the districts submit the data directly as is done in most states.

The DQC further touts Florida's system by noting the warehouse's ability to provide data for use in accountability reporting; to produce reports within 2-3 weeks of data submission; to provide useful data to teachers and administrators themselves; and to serve as a *quid pro quo* negotiating tool in which researchers are provided access to data in exchange for fees or the execution of analyses of interest.

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Utah

The inciting force behind Utah data sharing efforts was a request by the then-governor for information on foster children. The question—“What happens to children who age out of foster care?”—was unanswerable at the time, despite ongoing efforts by the Utah Department of Human Services (DHS) to warehouse internal data and improve their analysis capabilities. Shortly thereafter, in 2004, the Utah DHS began working toward a system that would allow state agencies to share data related to children in foster care.

Initial Steps

Operating in an *ad hoc* manner, Utah’s DHS first began by matching their own records with data from the Department of Workforce Services, the Department of Health, and the Utah State Board of Regents. From there, the department became highly interested in the extensive data warehouse held by Utah’s State Office of Education (USOE). It quickly became clear, however, that exchange between the two departments would be difficult if not impossible in light of FERPA confidentiality issues. As FERPA legislation is of concern to all states striving toward data sharing, it is worth noting that the two initial MOUs set up between DHS and the USOE entailed the following: The first MOU established that, because the state of Utah technically serves as the legal guardian of all children in state custody, it was permissible for the “state” to view those students’ records. The second MOU established a connection between these two databases for the purposes of evaluation of educational outcomes: Specifically, the Department of Human Services was conducting research on behalf of the Office of Education, and access to student-level data could therefore be granted.

Lessons Learned

Despite these positive steps—as well as the positive action Utah was able to take in response to the analysis of these two datasets—the exchange also revealed a good deal of weakness in both data systems. High levels of student mobility, missing test scores, and other weakness in the existing educational dataset have spurred Utah’s continued efforts to improve all data systems. Among the primary lessons learned was that an agency’s own data systems need to be strong and complete to serve the agency’s own needs, and to allow for any subsequent, successful efforts toward data sharing. Case in point, the Utah Department of Health has

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recently put out an RFP for probabilistic record matching software that will allow the department to better track its own clients over time and across the state.

The Benefits of Data Exchange

“As a result of connecting these data systems, Utah uncovered the staggering facts that children who age out of foster care earn wages below poverty, have high arrest rates and teenage birth rates, have low participation in follow-up services, and often do not have a driver’s license. Consequently, the state was able to coordinate efforts to address these deficiencies and increase basic services, such as health care, driver’s licensing, food stamps, follow-up services, and referrals to job and education training. The data not only created the impetus to act, but also provided policymakers with the information needed to target assistance and achieve their ultimate goal of improving outcomes for this crucial group.”
(DQC, 2006)

Colorado

In the hope of gathering very specific information on Colorado’s ongoing activities with criminal justice data and cross-agency data sharing, CPPR staff interviewed representatives from the state’s Court Administrator’s Office and the Colorado Department of Human Services. The following descriptive information and overview of best practices provides a measure of insight into one narrow—but highly useful—band of data sharing activity.

The Colorado Family Justice Information System (FAMJIS) project began in 2003 with the federally sponsored Strengthening Abuse and Neglect Courts in America (SANCA) project, which included a \$156,000 grant to help support the exchange of data between courts and the Colorado Department of Human Services to track permanency, safety, well-being, and due process for dependency cases. Today, the FAMJIS uses cutting edge technology to greatly enhance the ease of thoroughness of courtroom case management, and has become critical to both court-case efficiency and the legal decision-making processes.

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Known to stakeholders as “Virtual Family Court,” the FAMJIS offers at-a-glance information about all previous and current cases involving a given family that comes before the court. One key element of the FAMJIS system is its placement of the child, rather than the case, at the center of the system. All other information is built around the child’s key familial relationships—a data structure that gives the judicial officer a comprehensive view of the child’s case, placement, treatment, and services history. On the same computer screen, a judicial officer can view a wide range of pertinent information, including active warrants, protection orders, and all available child support information.

In the longer term, the FAMJIS mission is to develop effective business, management, and information systems to keep children in safe and permanent environments, and to achieve improved outcomes for families. In support of this mission, FAMJIS stated goals include:

- Improving data integrity through the development of best business practices.
- Collecting relevant information for staffing models and resource allocations.
- Developing more complete, accurate, and timely information for judicial officers.

Centralized information access is already fully implemented in child welfare and dependency cases and substantially underway in child support cases. The FAMJIS team is projecting full functionality in all child and family cases in 2009. Appendix P provides detail about Colorado’s data sharing laws.

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COUNTY BEST PRACTICES

As part of the current project, CDSS also requested a summary of data sharing arrangements, obstacles, and benefits among agencies in several key California counties. Best practice models at the county level, of course, may prove highly informative in the development of state-level models. To that end, data sharing possibilities, data sharing obstacles, and potential benefits of linking county data systems were discussed with officials from key county agencies. Information from meetings with county officials (which were conducted via telephone and face-to-face interview) is therefore included in the present report, with information from the following counties being provided: Los Angeles, Santa Clara, San Diego, and San Mateo. The greatest level of detail is presented on Los Angeles County due to the high number of children involved in the county's welfare system and the county's long history of experience with relevant data sharing challenges. Los Angeles County will, therefore, be highlighted, with additional information on the remaining counties briefly outlined.

Overview of Findings

Data sharing considerations for counties differ in important respects from those of state departments and agencies. Whereas CDSS, for example, needs to report to the federal and state governments in response to CFSR and AB 636, the counties need to share information to protect children from harm, coordinate direct services to children and families on an immediate and long-term basis, track families, and project future county-level trends and needs. In addition, counties themselves differ in how conservative or liberal they are in interpreting federal and state laws: Los Angeles County, for example, is fairly conservative, perhaps given the extent of funding they could lose for violations.

Several counties have established MOUs for data sharing, but they are not necessarily implemented. Several counties point to the need to change federal law or for the State of California to obtain a waiver from current laws, such as from HIPAA and FERPA. Legal change at the state level was said to be insufficient. Others felt that federal laws such as HIPAA do not stand in the way. It is generally accepted that privacy/confidentiality rights are important, but that

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current laws could be carefully interpreted or new laws written that would permit a better balance so as to optimally serve children and families in the child welfare system.

Due to lack of data sharing, there is duplication of services and hardships on families. For example, if two agencies are both required to conduct drug testing of parents but cannot share data, the family must submit to weekly drug testing by both agencies. This is costly financially and in terms of human capital. Moreover, data sharing could result in far better case management and even in saved lives, for example, when the DMH needs to know that reports of child abuse are occurring, or when the Department of Child and Family Services (DCFS) needs to know of a parent's or child's mental health or substance abuse problems.

Los Angeles

The Los Angeles DCFS recently entered into a data sharing agreement with several Los Angeles county agencies. Specifically, an MOU was signed July 1, 2007 to permit data sharing at the county level among DCFS, the Probation Department, the Department of Health Services, and the DMH (see Appendix Q). This MOU permits data sharing to the extent possible under the law.

The Katie A. lawsuit gave Los Angeles County the opportunity to improve coordination of their services. As a result, the benefits of data sharing became an option. *Katie A. v. Bontá* is a class action lawsuit filed against Los Angeles County, its DCFS, and county and state officials by the Western Center on Law and Poverty, and various other public interest organizations in July 2002. The suit was filed on behalf of a group of children in foster care and claimed that the state and county were unlawfully denying foster youth intensive individualized mental health, behavioral support, and case management services. The lawsuit was settled in 2003 with the county committing to improve the foster care system. The suit was named for Katie A., a 14-year-old child who had been shuffled through 37 placements during her 10 years in the foster care system. In another matter, a recent case involving a 5-year-old boy who was abused and tortured by his mother and her partner is also bringing pressure on Los Angeles to better coordinate services to children in abuse and neglect cases.

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Los Angeles Department of County Counsel

The Office of County Counsel provides legal representation, advice, and counsel to the Los Angeles Board of Supervisors, county departments, special districts, and other public agencies, as mandated and authorized by the Los Angeles County Charter and State statutes. The Office offers a broad range of legal services directed at promoting the public service objectives of the County, while protecting the County from loss and risk. The services include advising on the law as it applies to County operations; drafting legal documents; and representing the County in dependency court cases.

Overview of Findings

According to County Council, numerous laws have been proposed to allow and encourage data sharing; however, these efforts have been thwarted due in part to the numerous interpretations of federal laws relevant to data sharing. The Los Angeles Board of Supervisors is supportive of data sharing and suggests that data sharing may be feasible for children in the child welfare system if there is parental consent. However, the parental involvement in this process is contingent on the whereabouts of the parents. There may be a possibility to have a judge sign off in lieu of absent parents, yet this may not be practical given the large number of minors. By law, multidisciplinary teams of representatives from various agencies are currently permitted to share data in child abuse and neglect cases. However, this is only permitted on a case-by-case basis.

Statewide Automated Child Welfare Information System (SACWIS) restrictions were mentioned as obstacles to electronic data sharing. There is oversight of the statewide system (CWS/CMS) so that the Federal government can monitor it. It was felt that the federal government worries about monitoring a system developed by counties that overlaps with CWS/CMS. In 2003, a State grant for \$1.5 million was spent on developing a Los Angeles data sharing system. Los Angeles County department representatives met for two years to work out details of a data sharing plan and electronic database. However, the federal government reviewed the plan and would not support it financially because of SACWIS restrictions on overlapping data fields between CWS/CMS and any county data systems. This, in effect, ended that effort to have an electronic data sharing system. It was mentioned that even if privately funded initially, the

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federal government will not support projects on data sharing when there are features that overlap with CWS/CMS (but see Appendix R).

Current Data Collection Practices and Projects

Currently, there is an MOU signed by DCFS, the Department of Probation, the Department of Health Services, and the DMH. The MOU was developed because it was understood that the health and safety of minors depends on coordinated, holistic efforts rather than individual, fragmented efforts. The operative principle of the MOU is that those who have custody of the minor also have the health and mental health information they need to provide the minor with health and safety.

Although the MOU permits data sharing across certain departments, there are restrictions and guidelines that must be fully understood and followed. If data sharing is not carried out properly, the department could lose its funding. Because the consequences are severe, many people within the departments are reluctant to partake in data sharing. As an alternative, multidisciplinary teams are developed to share information and tackle special cases. For some purposes, Welfare Code 827 permits access to certain types of information. However, permission to share data on issues such as adoption, alcohol, and AIDS may require a court hearing.

Data Sharing Challenges

The cardinal obstacles to data sharing are the federal laws that emphasize confidentiality. These laws place limitations on what can be shared and under what circumstances. If these laws are not followed, administrators fear that funding to departments can be terminated.

Perhaps relatively unique to Los Angeles County, there is concern for the protection and confidentiality of the records of high-profile celebrities. An additional challenge for Los Angeles is that attorneys there are very proactive and readily bring civil actions. Such concerns add to Los Angeles County's vigilance of their records and carefulness with data sharing.

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An additional challenge stems from a lack of agreement on the interpretation of laws such as HIPPA and FERPA. As an example, there is a law that permits social workers to obtain educational records; however, FERPA will not permit such data sharing. Schools are frequently threatened that if they provide such information, they can lose their funding.

Data Sharing Activities and Benefits

At present, much of the data sharing is done informally through faxes and e-mails, to the extent possible legally. Benefits of electronic data sharing include better case management, coordination of services, and projection of future trends and needs. Certain court decisions, most notably the Katie A. law suit ruling, have put pressure on agencies for data sharing so as to better coordinate services.

The Los Angeles County Department of Child and Family Services

The Department of Children and Family Services (DCFS), with public, private, and community partners, provides child welfare services and supports in hopes children will grow up safe, healthy, educated, and with permanent families.

Overview of Findings

Los Angeles County is the second largest county in the nation with eight DCFS service planning areas (Antelope Family to South Central/Compton). Los Angeles County alone has 24,000 children in out of home care and 17,000 in temporary foster care.

Current Data Collection Practices and Projects

DCFS collects data that goes into the statewide CWS/CMS system. They also contribute to the Family and Children's Index (FCI; see Appendix S). The FCI, initiated in 1991 based on Assembly Bill 3491, is a computerized interagency data information system with over 1.7 million records of basic data regarding relevant contacts made between family members and various social service, health, and law enforcement agencies. In principle, the law permits educational data to be included as well. Regarding access, heads of "provider agencies" and their designated representatives, in addition to members of multidisciplinary personnel teams as

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defined in existing law, may access the data when they believe such information is relevant to the prevention, identification, or treatment of child abuse or neglect.

Participating Los Angeles County departments (e.g., DCFS, DMH, and DHS) identify at-risk families and children and provide basic identifying information as well as pertinent data on contacts and events. An FCI check is conducted on all new referrals. Before accessing protected health information, a multi-disciplinary team is formed on a case-by-case basis.

On another note, DCFS has consulted with Allegheny County, Pennsylvania, about their data sharing system as a possible model for Los Angeles. As described later, Allegheny County consolidated several county agencies under one umbrella organization thereby facilitating data sharing.

Data Sharing Challenges

Data sharing regulations for DCFS are found in Title IV-E and CAPTA. Certain exceptions exist (e.g., see 45 CFR 205.50). For example, although CAPTA requires states to preserve confidentiality of all child abuse and neglect records, CAPTA allows the State to release information to entities or classes of individuals who are authorized by statute to receive information pursuant to a legitimate State purpose. Moreover, the State *must* provide child abuse and neglect information to federal, state, or local government entities, or any agent of such entities, that has a need for such information to carry out its responsibilities under law to protect children from abuse and neglect (see Appendix T).

In addition to the federal laws, a major data sharing challenge in Los Angeles for DCFS is that part of the Los Angeles County Counsel office takes a conservative approach to data sharing, whereas other parts of that office are less conservative. The CEO and County Counsel offices are working to reach agreement. DCFS notes that the CEO of Los Angeles is quite interested in data sharing and is establishing a Service Integration Bureau within the CEO's office.

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Data Sharing Activities and Benefits

Several benefits to data sharing were mentioned by Los Angeles DCFS. First, to the extent that data sharing results in better coordination of services, children will more often be able to remain in their homes safely. This is vital for child welfare and for society. Second, parents will be better able to succeed in raising their children if agencies are not making duplicative and often conflicting demands on parents. Third, the ability to share data will provide the opportunity for macro planning based on trends and correlations in the data. This information is valuable, for example, for predicting and preparing for economic downturns, during which there may be an increase in child abuse of certain types. Awareness of trends can help ensure early intervention.

The Los Angeles County Office of Education

The Los Angeles County Office of Education (LACOE) offers integrated, educational programs, and services, from birth to adulthood. LACOE provides direct instruction to juvenile offenders (juvenile court and community schools), pupils with disabilities (special education), and students who are at risk of dropping out or who need alternative classroom settings (alternative education). In addition, LACOE operates the county's Head Start-State Preschool program, which is the largest in the nation.

Effective January 1, 2004, AB 490 (Steinberg), Chapter 862 imposed new duties and rights related to the education of dependents and wards in foster care (e.g., it authorizes the release of educational records of foster youth to the county placing agency, for purpose of compliance with WIC 16010, case management responsibilities required by the juvenile court or law, or to assist with the transfer or enrollment of a pupil.). To ensure rights and stability for children in foster care, LACOE maintains a Foster Youth Services division. This reflects a state-funded program serving the educational needs of youth living in foster care. The mission of Foster Youth Services is to improve the educational outcomes for students residing in foster homes through a multidisciplinary approach.

Overview of Findings

There are 80 school districts in Los Angeles County, which educate 1.7 million children in county schools. Nearly half of California's 75,000 foster children reside in Los Angeles County.

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Many of these children qualify for special education, although their high mobility interferes with timely and appropriate placement. There are also 85 school sites for CAL SAFE (programs for expectant and parenting students). Approximately 15,000 youth are in court schools (e.g., within juvenile halls and camps for delinquent children) in Los Angeles County.

In June, 2006 the Honorable Michael Nash (Presiding Judge of the Los Angeles County Dependency Courts) signed a court order relevant to data sharing for children in the child welfare system. However, even under this court order, whoever has education rights for children still has to provide consent for sharing of educational data due to FERPA regulations. Finding out who has educational rights for a foster child can be challenging. Moreover, although every child who leaves dependency court hearings is supposed to have documented educational information, many children leave the courtroom with incomplete forms.

LACOE participated in the two year effort, funded by the State of California, to develop a data sharing system for Los Angeles. Although this effort failed due to lack of federal funding, LACOE would be happy to try again.

Current Data Collection Practices and Projects

LACOE has its own electronic data system, with a detailed on-line data dictionary that spans 2000 pages. LACOE is permitted to share data with other educational entities within California. LACOE currently sends data to the State Department of Education as part of the California School Information System. LACOE is looking forward to implementation of the California Longitudinal Public Assessment Data System (CALPADS), which will be an improvement over the current state data system and will include much more detail about students.

Foster Youth Services is funded by the State Department of Education. Each county has such funding, and counties are permitted to share relevant data within the Foster Youth Services system. This information is contained electronically within the broader LACOE data base.

If a court subpoenas LACOE data, LACOE can share data with the courts. LACOE can also share some information with the Los Angeles County Department of Probation.

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Data Sharing Challenges

FERPA is the biggest single obstacle to data sharing for LACOE. LACOE interprets FERPA as precluding sharing of data with CDSS. With rare exception, LACOE can share data only with other educational entities. Thus, if a social worker or probation officer calls to obtain educational information on a child, legally LACOE can only send that information to an educational unit, unless someone with educational rights has provided consent for data sharing for that child. As mentioned, two exceptions are through court subpoena and data sharing permitted by FERPA with the Los Angeles County Department of Probation.

Because of the lack of data sharing, LACOE does not necessarily know if a child is a ward of the court or in foster care, unless the child or family discloses such information. The same potential lack of information is true for teachers and school psychologists. LACOE does not have access to the CWS/CMS database.

Data Sharing Activities and Benefits

Benefits for LACOE of greater data sharing include better compliance with regulations. For example, Child Find (a component of the federal Individuals with Disabilities Education Act) is a process to determine if a child is eligible for special education services. Because many children in the child welfare system may qualify for special education, identifying such children would be facilitated by child welfare information.

Another benefit would be for children who need Individualized Education Programs (IEPs). At present, if LACOE cannot know which children are in the child welfare system, it can be difficult to know who has legal authority to sign off on children's IEPs.

Benefits would also follow from foster parents obtaining more information about foster children. At present, social workers often feel restricted in what they can tell foster parents about foster children's backgrounds. As a result, teachers and schools cannot count on such parents to know children's histories and needs. Moreover, LACOE is sometimes working with children who are runaways or street children, for whom parents cannot be found. It is sometimes difficult to find out the last school such children, as well as foster children generally, were in. Overall, as for

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other departments, benefits of electronic data sharing include better services to children, better coordination of services, and projection of future trends and needs.

The Los Angeles County Department of Mental Health

The Los Angeles County DMH serves approximately one-quarter of a million residents each year, making it the largest mental health service system in the nation. It provides a diverse spectrum of mental health services to all ages, including such services as mental health assessments, crisis intervention, case management, and medication support in both residential and outpatient settings. The Department's workforce includes psychiatrists, psychologists, social workers, medical doctors, clergy, and trained mental health consumers.

Overview of Findings

DMH falls under HIPAA. However, according to DMH, HIPAA permits data sharing concerning treatment, payment, and service coordination.

The Kate A. suit is particularly relevant to DMH, as well as DCFS. In the suit, it was charged that the Los Angeles DCFS failed to assess mental health needs among the 50,000 foster children in its care and that, once children with emotional and behavioral impairments were identified, they received few services. As part of the settlement, Los Angeles County agreed to offer intensive, family-based "wraparound" care to children with mental, behavioral, or emotional disorders, using flexible funding to pay for a wide range of services that are individually designed to meet the needs of each child and family. To address the requirements of the settlement, Los Angeles County Counsel asked the judge to approve data sharing, which resulted in DMH and DCFS providing the CEO of Los Angeles County with data sets that were matched by the Urban Research Branch of the CEO's office to determine the subset of individuals served in common by DMH and DCFS. Unfortunately, this system of data sharing is indirect and slow, at least for county needs.

Current Data Collection Practices and Projects

DMH has an existing legacy mainframe-based Mental Health Management Information System (MHMIS) and a web-based "wrapper" of the MHMIS known as the Integrated System (IS), which

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was implemented in 2004 to meet HIPAA Transaction and Code Set requirements. In November 2004, voters in California passed the Mental Health Services Act (Proposition 63). Proposition 63 provides an opportunity for DMH to reengineer the way it delivers mental health services, but it also requires significantly improved automated support to meet expectations for performance and outcome measures reporting. DMH cannot meet Mental Health Services Act program transformation and reporting expectations with its current automation. DMH is thus currently seeking a commercially available off-the-shelf integrated software application to support its business operations in its dual role as provider of mental health services and administrator for a network of contract mental health service providers. Once installed and fully implemented, this software will be known as the Integrated Behavioral Health Information System (IBHIS).

The ultimate goal of DMH is to migrate to a paperless environment by obtaining a product that will enable the Department to meet the federal and state guidelines for an Electronic Health Record (EHR). The proposed system will replace MHMIS and IS. Of note, IBHIS also:

- Establishes the foundation for improved ability to exchange data electronically and securely with business partners such as contract providers, Department of Health Services, Sheriff (Jail Mental Health), Superior Courts, DCFS, and Probation (County Strategic Plan – Goal 7); and
- Allows clinical and administrative data in digital format to become a potential source of information for client Personal Health Records.

Data Sharing Challenges

For DMH, technology is not an obstacle to data sharing. Moreover, HIPAA is not viewed to be as much of an obstacle as some believe. Instead, interpretations of federal laws are the main obstacles. Nevertheless, certain laws do make it particularly difficult to share data with DCFS, as well as with certain other agencies such as those dealing with drug and alcohol programs. Moreover, children's attorneys may have an interest in blocking data sharing if such sharing could implicate child clients of wrong doing.

What would be most useful for DMH is to have on-line *immediate* matching and data sharing. For instance, the results of the social worker's mental health screening of a child could go

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immediately into a database to be shared with DMH. Presently, when the CEO's Urban Research unit provides a match, a 6-month period might pass. This is too slow for optimal case management and mental health services for children in the child welfare system.

Data Sharing Activities and Benefits

Multidisciplinary teams are formed, as possible, in which the primary goal is to share data with DCFS. DMH has also at times deputized individuals to enable data sharing. DMH has staff at DCFS offices who receive referrals for children who may need mental health services. DMH staff partner with law enforcement to share information verbally. The DMH signed the Los Angeles County MOU (Appendix Q) referred to earlier in this Chapter.

In terms of benefits, DMH has obligations to report information to the federal government, including certain granting agencies, such as SAMSHA. Data sharing could be useful in meeting these obligations.

Benefits to DMH and to the state include better outcome data (e.g., life outcomes of patients, school outcomes, and family stability). Such information is crucial for making positive changes, providing feedback to service providers, and developing baseline information.

The representatives from the DMH indicated a specific interest in sharing data with DCFS. Immediate information may be important for helping children in crisis situations. Overall, it is thought that data sharing would result in better case management.

The consequences of the DMH and DCFS being unable to share data often affect the most vulnerable people. A tragic anecdote makes the case clear: A father in Los Angeles had joint custody of his daughter while the child was receiving treatment from the DMH. There were many reports to child protective services against the father; however, this information was withheld from DMH. Eventually, the father said the child wanted to quit treatment and that she had stopped taking her medications. The child then committed suicide. This case demonstrates, quite vividly, the need for data sharing and for a team approach to handling complex cases.

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San Diego, Santa Clara, and San Mateo

There is considerable overlap in data sharing considerations across California counties.

Therefore, many of the same themes as already mentioned for Los Angeles are relevant to other counties as well. However, here we note some exceptions or salient issues regarding San Diego, Santa Clara, and San Mateo counties:

San Diego County

San Diego County's Superior Court has local rules that permit certain types of data sharing in that county. (See San Diego Superior Court rules, Division 6 – Juvenile, Chapter 6, Access to Confidential Information, http://www.sdcourt.ca.gov/portal/page?_pageid=55,1120217&_dad=portal&_schema=PORTAL.) San Diego also has a number of blanket court orders that deal with the sharing of child welfare information. Each order is issued to authorize sharing certain types of child welfare services information (e.g., health information, education) with a specific agency (e.g., Casey Programs, researchers). San Diego County has developed data sharing agreements specific to corrections and re-entry issues—agreements that could serve as partial models for child welfare services (see Appendix U).

Santa Clara County

Although the Santa Clara Countywide data warehouse (called Cross Systems Data Warehouse) was worked on for several years, the project was discontinued a few years ago. Thus, at present, there is no data warehouse.

In considering data sharing in Santa Clara County (e.g., through a data warehouse), issues arose concerning unique identifiers, consent, and accuracy of data input, as well as federal confidentiality laws. Over the years, County Counsel and private foundations have been involved in discussions of data sharing, and some progress has been made.

Specifically, an MOU exists in Santa Clara County for electronic data sharing, spearheaded by their Education Office. The MOU includes the Department of Family and Children's Services (DFCS), the juvenile courts for both dependency and delinquency, three school districts, and juvenile probation. As part of this MOU, the Social Services Agency Information Systems

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Department of Santa Clara's Social Services Agency has started sharing data on a pilot basis with the County Office of Education. Their data sharing agreement was modeled after that in San Diego. Although, in contrast to San Diego, the model has not yet resulted in successful electronic data sharing aside from the pilot work, movement in that direction is clearly occurring.

Santa Clara County has a new data base ("Efforts to Outcomes") relevant to independent living for emancipated foster youth (age 18 to 25 years). Data are shared with DFCS and independent living providers.

San Mateo County

San Mateo Child and Family Services (CFS) has MOUs with mental health services and also with juvenile probation to share aggregate data (see Appendix V). Moreover, San Mateo CFS is currently working on an MOU with Alcohol and Drugs, which is now part of Mental Health Services. In general, San Mateo's Human Services Agency uses MOUs/contracts when sharing CWS/CMS information. CFS normally distributes aggregate data and shares them with other county agencies whenever it is deemed to be useful. For example, CFS freely shares the AB 636 data (with Citizens Review Panel, posting on internet), and CFS has shared disproportionality data at strategic planning meetings where community partners were present.

San Mateo CFS has a data warehouse maintained by BSG, but it does not combine data across agencies. BSG produces ad hoc reports and break downs from CWS/CMS.

San Mateo has a "System of Care" wherein CFS, Probation, Mental Health, Education, and Drugs and Alcohol departments all meet once per month to go over service delivery.

Allegheny County, Pennsylvania

Because of its innovative approach to data sharing, one county from outside of California is described here. Just over a decade ago, Allegheny County, Pennsylvania, restructured a number of its county organizations to bring several separate departments together under one umbrella. The resulting new entity—called the Department of Health Services (DHS)—was then responsible for services related to Mental Health, DCFS, Welfare, Mental Retardation, Drugs

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and Alcohol, and Homeless Services. Because of this organizational structure, DHS considers its staff to work for DHS, not individual areas such as Child Welfare or Mental Health, and therefore can share information across the agency. The majority of the funding for Allegheny's DHS came (and still comes) from the State Department of Public Welfare, as well as from some federal sources. At the state level (i.e., in Pennsylvania as a whole), comparable departments are *not* united under one agency. Yet it is this key structural difference that allows Allegheny County to share data to the extent DHS does: Because the State recognizes these various county departments to fall under one umbrella and represent one large organization, the departments are permitted to “share” data across the various disciplines handled by DHS, with the exception of data from their Drugs and Alcohol programs. Child Welfare Services and Mental Health is the most common cross system, since a high percentage of children are served by both programs.

Overview of County Data Sharing

Today, depending on which services individuals receive, there may be different program-specific information collected on them; however, everyone served by Allegheny County's DHS has only one demographic record housed in their Master Client Index. Thus, if someone is involved in child welfare services and goes in for drug testing through the Drugs and Alcohol program, the person's name comes up on the computer screen with demographic information to check if it is, indeed, the same person (e.g., same name, same address). It is important to note, however, that the Master Client Index contains only demographic information, but that DHS is currently working to expand their capabilities by adding a family index that will allow them to track services at this level as well.

Over the past 6 months, Allegheny County has also been working on a DHS “Children Serving” system. Under this system—which is still in the planning phase—any child who comes in through the door would be tracked. County officials indicated their hope that Drug and Alcohol data would eventually be included in this tracking system, but the future of those plans remains unclear.

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Many of the services provided by Allegheny Country are contracted out. Regardless, the contracted agencies are required to have families fill out a form attesting to the fact that any collected information will be shared with DHS. This is a contractor form as opposed to a state or county form. Under this system, however, child welfare workers do remain *county* workers, and they too have data sharing forms for parents to complete. Once within DHS, all collected information can be freely shared across the department, which is currently moving toward a more cohesive electronic data sharing system that will be capable of handling all departmental information.

Allegheny's DHS currently maintains a data warehouse, which combines data across its various "departments" – county jail, juvenile probation, and medical examiner information. The data are primarily used in aggregate form for planning and research, with DHS maintaining the warehouse and developing all data applications. DHS officials are planning to add Head Start data in the near future—despite the fact that Head Start data fall under FERPA: Because Head Start money goes to DHS, it can legitimately say that Head Start falls under its umbrella. In terms of HIPAA, DHS does adhere to strict privacy guidelines regarding its behavioral health (mental health and drug and alcohol) data and has minimal physical health data (only on children in placement in the child welfare program).

Regardless, DHS's data warehouse has proved extremely useful for research purposes. For example, Carnegie Mellon University, University of Pittsburgh, and the Rand Corporation have all accessed the DHS data warehouse for these purposes. The criteria for data sharing for research are looser than for government program work, and the data are first de-identified and aggregated (or a false ID is provided). DHS notifies all relevant agencies when data are de-identified and given out, but DHS does not have to receive formal agency approval to do so. The exception to this rule is information on domestic violence and HIV, which is not given out, even at an aggregate level. See Appendix W for a list of the departments that contribute data to the warehouse, as well as information on key data elements housed in the warehouse. Thus far, Allegheny County has received no legal challenges to its operations.

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State Level Activity

At the State level, Pennsylvania takes part in far less data sharing. Due to the State's interpretation of federal law (as well as the incompatibility of the departments' existing data systems), information is still silo'ed quite separately. Due to the particular strictness of laws related to drug and alcohol information, these data cannot even be shared with counties, or at the county level. Currently, the two departments taking part in the most data sharing at the State level are Child Welfare Services and Mental Health. Pennsylvania also does not have an electronic data system that is equivalent to CWS/CMS, but has recently contracted with a consulting group to look into the possibility of developing a statewide data system.

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CONCLUSION

Since the early 1990s, public bodies, professional organizations, and business groups have called for greater interagency coordination to achieve a more comprehensive approach to providing services to children and families (Soler, Shotton, & Bell, 1993). CDSS, with the support of CWC and numerous other state agencies, is well on its way toward the eventual achievement of this monumental task. As the information contained in this report clearly reveals, crucial data on child well-being are being shared by other states, by numerous counties, and (in nascent forms) by CDSS and several of the interested agencies covered in this report.

Data partnerships offer the possibility of a more thorough understanding of the difficulties endured by children and families involved with child welfare services. They also have the power to deflect some of the problems such children might face (Slayton, 2000). In child welfare cases, specifically, when case workers have access to multi-agency information, they can better advocate for their clients (Ehrle, Malm, Fender, & Bess, 2001). Furthermore, an integrated system not only enhances the data themselves by offering greater consistency of collection, greater standardization of definitions, and (potentially) greater security of storage, it provides an overall improvement in the seamless alignment of information transmission and utilization across all systems (Data Quality Campaign, 2008).

In addition to these client-oriented imperatives for data sharing are the more operations-oriented motivators, including federally mandated reviews and the desire (and necessity) to reduce duplicated efforts, address inefficiencies and inaccuracies, allow for thoroughly informed program planning, and eventually reduce costs and workloads for each individual department. This will take time and a concerted effort, supported by legislation and some initial influx of funding. While

Information sharing does not occur in a vacuum. There are policy, legislative, political, and environmental concerns to be addressed, in addition to the underlying technology which makes it possible. By understanding these issues, one is better prepared to navigate the hurdles that are faced by those working to share information, but are not always empowered to do so. (United States Department of Justice, 2007)

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there can be no doubt that the state of California is facing difficult financial challenges, effective data sharing enhances the State's efforts toward improvement of service provision at the client level and increased efficiency at the operations level. Additionally, developing progressive, high-quality data systems now is an investment in future State endeavors. The current economic situation forces operations and client service be focused on efficiency, and data sharing is an area where progress toward increased efficiency can surely be made. Improvements and developments in sharing data among state agencies can happen despite—and perhaps *must* happen because of—California's budget limits.

The current report—completed for CDSS on behalf of the CWC—represents another step toward the formation of a comprehensive plan for data integration. By being comprehensive, this report takes into account the diverse nature of the issues faced by individual departments (e.g., the primary challenges being technological for some and legal for others), as well as the need to craft a long-range plan that takes the needs of both the State and its counties into consideration. Whereas counties want to access multiple data sources for the purposes of individual case management, case worker reviews, and program planning, the State needs to respond to state and federal performance measures, demonstrate ongoing improvements in services and operations, and find a way to move its disparate 20th century technologies into more streamlined 21st century systems.

Data Sharing Challenges

In reviewing our investigations into the eight departments covered in this report—as well as a wealth of federal, state, and county-level research—several major themes emerged in terms of the data sharing obstacles. These themes—which often presented themselves in terms of challenges or barriers—cannot be ignored, but can most certainly be addressed. Looking at logistical and organizational impediments to data sharing, the following summarizes CPPR's major findings:

Confidentiality and Privacy

The invasion of privacy poses an implicit threat to many people. Yet before one can overcome or even address this obstacle, the definition of confidentiality and privacy rights and protections

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needs clarification. "Legally, agencies cannot act outside the power delegated to them under the authorizing statute" (Dawes, 1996; Harmon & Cogar, 1998). As agencies are not permitted to collect data beyond that mandate, inherent challenge arises when any other entity requests access to those data. Not even MOUs provide a consistent solution; they are typically written to be narrow, addressing specific programs rather than ranges of programs or entire databases. On the one hand, those who feel hesitant about data sharing often prefer to rely on the structures of statutory authority, rather than to challenge it. Advocates for interagency sharing, on the other hand, view statutory guidance as an encumbrance or as an over-applied principle that serves many purposes while thwarting many potential improvements in the way the State provides services. "While there is certain ambiguity in any statute, the large amount of ambiguity, and even a lack of vision of this 'information sharing thing' invites abuses by overreaching administrators or non-action by timid bureaucrats" (Landsbergen & Wolken, 2001, p. 209). To reduce such ambiguity, a model code of laws needs to be developed to overcome the current confusion.

The majority of the people CPPR interviewed for this report alluded to the restrictions imposed by either HIPAA or FERPA. After examining the actual language and the intentions of both laws, however, there seems to be much room for discretionary sharing of data. In fact, actions falling short of proactively serving students and people with difficult medical conditions necessitate a closer reading of both documents. FERPA's actual mandate, for example, suggests sufficient leeway in the educational and juvenile systems to share data *to better a child's welfare*. Likewise, HIPAA's mandate allows the freedom to share health information aimed at providing quality health care for individuals and quality services for the population at large. Compared with the findings from CPPR's 2006 research report, state agencies are now generally more informed about HIPAA and FERPA, exploring how to consider these statutory provisions rather than citing them as reasons not to share data.

Insufficient Funding and Human Resources

Why should an agency spend its scarce resources on an interoperable endeavor when the benefits are ill-defined and the costs unclear? Isaacs (1992) asserts that long-term, stable funding frequently does not exist for interagency partnerships. Programs suffer because they

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lack sufficient time and human resources to provide a continuity of services while also overhauling major systems of operation. Nearly all California state departments interviewed for this study cited a lack of human resources to conduct various tasks needed for data sharing (e.g., data matching, quality assurance, data extracting) as impediments not only for inter-departmental data sharing but frequently for intra-departmental data projects. It will be important for the CWC to consider these limits on financial resources as recommendations for improvement of data sharing are created. One possible option is to stratify those recommendations by cost. There are some no- or low-cost activities which could be undertaken quickly (e.g., thorough dissemination of resources already developed and available such as template MOUs and interagency agreements, formalized communication between agencies' counsels to clarify legal options for data sharing that do not require additional technological or human resources).

Insufficient funding offers another downside to data sharing. With many crucial programs barely surviving, the prospects of contracting for advanced technological support, updating software and servers, generating new positions, and building new infrastructure can be expensive. Pay inequalities between the public and private sector also make it difficult for the state to recruit, hire, and retain top-shelf technological talent. Reports from information technology staff at state agencies describe a regular drain of experts to private sector firms, frequently working under contract with state agencies.

Data Quality

Permeating the literature on data sharing is the difficult-to-conquer fear agencies have about the quality of data generated by other agencies. A sense of personal ownership, as well as personal experience with the challenge of maintaining massive amounts of high-quality data, often lead agency personnel to express concern over what, exactly, they would be receiving and how reliable that information may be.

In the current study, agencies expressed concern that the local jurisdictions entering data (e.g., county agencies) may not know or appreciate all the ultimate uses for certain variables, leading to inconsistent or unreliable data entry. A county practitioner, for example, may view a data

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system purely as a case management, or client-oriented, tool when it is equally critical as an operations-oriented system used to assess performance management. Operations-oriented staff members are viewed as the “data people,” whereas client-oriented staff members are the “program people,” yet both groups use and rely on the same data sets. Because the quality of shared data is critical, issues relevant to data quality deserve thoughtful attention.

Departmental Silos

Another significant barrier to improving child and family outcomes is the widespread "silozation" of human services technology within state governments. Different funding sources, accountability measures, and competing agency priorities can result in dozens of separate technology systems serving the same families. Incompatible systems result in duplication, poor service delivery, and inefficient use of resources. Data frequently remain isolated, even within the same department. These silos are reinforced by distinct accountability and performance measures from federal and state agencies. Few performance measures align across all departments, but all departments express interest in accessing more data from sister departments to potentially help meet performance measures and improve services.

During the present investigation, it became increasingly clear that individual data on children receiving public services are being recorded and stored across a number of county and state agencies' databases. In fact, the amount of data for any individual child would potentially be overwhelming and redundant if all databases storing information for that child were somehow merged into one record in a relational database. Because most databases use unique identifiers for their particular data programs and no longer use a standardized universal identifier (i.e., social security number), linking these multiple sources of individual-level data can be daunting. California databases store a great deal of information on individual children receiving public services, but the state lacks a coordinated mechanism to link these data across programs and departments. Nevertheless, there are strategies to help overcome these challenges.

Performance and Outcome Measures

Best practices and public policy clearly indicate that agencies serving children and families involved in the child welfare system should monitor and evaluate their performance and the

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outcomes of those services (e.g., the Adoption and Safe Families Act of 1997). Data sharing can contribute to such monitoring and evaluation. The Judicial Council and the AOC have taken great strides in structuring a system for thorough, appropriate, and timely performance measurement through the adoption of Rule of Court 505.5. Of more importance, they intentionally designed these measures to align with outcomes of interest to CDSS. In this way, performance evaluation activity within the court system may also provide data useful for CDSS in their own planning, program design, data collection, and evaluation.

The DMH has developed a Performance Outcome Committee to oversee their efforts to collect point-in-time consumer satisfaction and client outcome data for all eligible persons being served throughout the mental health system. There are several other examples of performance evaluation efforts conducted by the agencies involved in the current report. Centralizing information about performance and outcome measurement across agencies would be useful in ascertaining commonalities in mandated state and federal reporting requirements as well as in identifying mutually beneficial data. The collection of data related to performance and outcomes is vital to ensuring that agencies provide appropriate, high-quality services to children and families involved with the child welfare system. One potential goal for California may be the development of uniform performance measures and attending data collection procedures that could be used across multiple agencies to increase collaboration and minimize duplicated efforts.

Data Sharing Strategies

Although detailed action plans for each department will differ somewhat, the following is a list of CPPR's overall conception of key strategic issues for moving forward. These general recommendations are based on both our 2006 SIT report, the current report, in-depth interviews conducted with experts from all over the country, and a review of the literature on data sharing best practices:

- Re-conceptualize the challenges of data sharing—as well as the benefits of data sharing—in terms of both client-oriented and operations-oriented points of view. The lack

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of direct connections between case management and performance management contributes to questionable data quality and diffuse commitments to data sharing.

- Establish short and long-range goals. Short-range goals can help create data sharing with existing structures and include MOUs, court ordered agreements, business associates agreements (for covered entities under HIPAA), initial pursuit of legislative changes, and the organization and mobilization of small, focused data workgroups. A number of California counties described in this report (i.e., Los Angeles, San Diego, San Mateo, and Santa Clara) have made tremendous progress with these short term goals, creating viable MOU templates and business associates agreements for inter-agency sharing.
- Long-range goals may include state-level and county-level organizational restructuring, the creation of data warehouses, advocating at the federal level for reinterpretations to various data confidentiality regulations, and overhauls of agency data systems to achieve a greater degree of standardization in data elements, definitions, collection processes, and programming languages. The current efforts of the California AOC and the “Virtual Court” in Colorado are good examples of long range planning involving legal, policy, and technological elements, along with political will and support to transform data into critical information for use in both case and performance management.
- Development of systems and technology should be based on the best models currently available rather than attempting adaptation of current—possibly outmoded—systems to work together. Adopting progressive data management systems at the outset allows for increased longevity of data sharing projects. Centralized data sources, or data warehouses, provide a one-stop option where data from multiple sources can be securely entered and matched confidentially to produce individual and aggregate client information (McDonald & Associates, 2008). Models of this approach include the National Center for Health Statistics (NCHS), which hosts a huge repository of electronic data designed to facilitate inter-agency reporting and analysis. Through the NCHS data warehouse, other agencies can search through multiple, inter-locking databases, for individual and aggregate data. Similarly, the DHCS MIS/DSS data warehouse translates various DHCS databases into one coherent description of an individual client for use by departmental staff.

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- Conduct further investigation into performance measures across state agencies to determine how data are being used to evaluate agency performance, and in what ways these measures overlap and inter-relate from one agency to another. Increased knowledge about performance measures may inform interagency collaboration, information sharing, and program evaluation strategies. Data sharing may benefit multiple departments and agencies in regard to their performance measures.

The keys to achieving any of these short and long-range goals are political will and multiple risk-sharing—the kind of will and risk-taking by which a number of California counties have realized significant results. Recent commitments by the Judicial Council, AOC, and CDSS, as well as the declaration by the Data Linkage and Information Sharing Committee of the CWC, toward improving data sharing strongly suggest that California has a measure of political will and is seeking additional risk-taking partners to enhance its capacity to share data. These initial steps along with the ongoing sponsorship of CWC and guidance from its many constituent partners, are signals that the discussion on improved data sharing on behalf of children may soon be moving from *How can we?* to *When do we start?*

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